DOCUMENT RESUME

ED 427 854 PS 027 342

AUTHOR	Lalley, Jacqueline, Ed.; Ahsan, Nilofer, Ed.
TITLE	Family Support & Health Care: Working Together for Healthy Families.
INSTITUTION	Family Resource Coalition, Chicago, IL.
SPONS AGENCY	Robert Wood Johnson Foundation, Princeton, NJ.
PUB DATE	1998-00-00
NOTE	37p.
AVAILABLE FROM	Family Resource Coalition of America, 20 N. Wacker Drive, Suite 1100, Chicago, IL 60606; Tel: 312-338-0900; Fax: 312-338-1522; Web site: http://www.frca.org; e-mail: frca@frca.org
PUB TYPE	Collected Works - Serials (022)
JOURNAL CIT	Family Resource Coalition Report; v17 n2-3 Sum-Fall 1998
EDRS PRICE	EDRS Price MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Agency Cooperation; Child Health; Children; *Family Health; Family Life; *Family Needs; *Family Programs; Health Activities; Health Needs; *Health Programs; Health Promotion; Health Services; Medical Services; Parent Role; Parents; Pediatrics; Public Policy
IDENTIFIERS	Access to Health Care; *Family Advocacy; Family Development; Family Resource Coalition IL; *Family Support

ABSTRACT

This report of the Family Resource Coalition of America examines partnerships between family support programs and health care providers, forged to ensure that the comprehensive needs of families are met. The report begins with two articles, "Family Support and the Emerging Health System" and "Social and Economic Issues Affecting Health--A Research-Based Argument for Family Support," which examine how family support and health care are linked. The second section presents three articles on improving access to health care: "How Your Program Can Help Get Coverage for Children"; "HMOs, MediCAL, and Bureaucracy-How My Program Helps Families"; and "What Families with Chronic Illness Need." Articles in the third section address linking pediatricians with family support: "Pediatricians as Family Support Partners"; and "Linking Pediatric Care with Family Support--How One Center Does It." The fourth section presents three articles on families as health care partners: "Parent to Parent--Help for Parents and Professionals"; "Mothers Mentor Teens as Paraprofessionals"; and "How I Got Involved in Allocating Health Care Funds." Articles in the fifth section address public policy to promote healthy families: "How States Can Remove Barriers to Health Care"; "CHIP of Virginia--A State Network Links Family Support with Health Care Services for the Young"; and "State Health Dollars Fund Family Support in Oklahoma." Finally, the sixth section presents articles addressing building healthy communities: "Montana Coalition Promotes Health and Quality of Life"; "Families Train Health Care Professionals in Family-Centered Practice"; "Alaska Nursing Students Forge Community Partnerships"; and "Asian Americans Get Culturally Supportive Care in Denver." (SD)

SUMMER/FALL 1998 Volume 17, Numbers 2 & 3

FAMILY SUPPORT & HEALTH CARE
Working Together for Healthy Families

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
X This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 427 854

PS 027342

FAMILY RESOURCE COALITION OF AMERICA

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL IN MICROFICHE AND IN ELECTRONIC MEDIA FOR ERIC COLLECTION SUBSCRIBERS ONLY HAS BEEN GRANTED BY
P. Deane
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
2A

BEST COPY AVAILABLE

Acknowledgments

FRCA would like to thank all of the family support and health care practitioners, advocates for families, and others who were willing to be interviewed and who took time from their busy schedules to write for this issue of FRCA *Report*. Their input allowed FRCA to devote these pages to the quickly growing and much needed collaboration between providers of health care and family support programs.

In particular, FRCA thanks Carol Pandak, Linda Paul, and Charlotte Zia of the American Academy of Pediatrics for taking the time to visit FRCA last spring and providing the inspiration for this issue. Thanks also to CHIP of Virginia and photographer Andres R. Alonso for providing select photographs for this issue. Many thanks to Charles Bruner and Maria Elena Orrego for guidance in developing the contents of this publication.

FRCA would like to thank Terrance Keenan of the Robert Wood Johnson Foundation for his guidance on this issue of FRCA *Report* as a whole, his insight on the relationship between health and family support, and his article detailing the importance of bringing together the two fields. Finally, FRCA is grateful to the Robert Wood Johnson Foundation (Princeton, N.J.) for its support of this publication and the Family Resource Coalition of America.

About the Cover

As well as providing activities for parents and children, Parents and Children Together (PACT) works with local agencies to provide comprehensive services—including medical care—to families in the Kuhio Park Terrace housing project in Honolulu, Hawai. Family health has improved since health care became part of a continuum of services and programs available to families in their neighborhood.

This photo and others are part of a nationwide photo exhibit tour and public education campaign, Pursuing the Dream: What Helps Children and Their Families Succeed. The campaign includes a photo book that shows community-based programs in action, and is a collaboration among FRCA, award-winning photographer Stephen Shames, and Aperture Foundation. For information on how to get involved or bring the exhibit to your community, contact FRCA.

Photo ©1997 Stephen Shames / Matrix

FRCA *REPORT*

Executive Director: VIRGINIA L. MASON

Associate Executive Director—
Communications, Publications, and Marketing:
KATHY GOETZ WOLF

Editors: JACQUELINE LALLEY and NILOFER AHSAN

Assistant Editor: JULIA DELAPP

Reporters: SONYA YOUNG and DANIELLE JONES

Copy Editor: ERIC SHUTT

Art Director: LYNN PEARSON

Graphic Production: TOM PETH

Printer: BOOKLET PUBLISHING

Family Resource Coalition of America is a membership, consulting, and advocacy organization that has been advancing the movement to strengthen and support families since 1981. The family support movement and FRCA seek to strengthen and empower families and communities so that they can foster the optimal development of children, youth, and adult family members. FRCA builds networks, produces resources, advocates for public policy, provides consulting services, and gathers knowledge to help the family support movement grow. For information or to become a member, contact FRCA at 20 N. Wacker Drive, Suite 1100, Chicago, IL 60606, 312/338-0900, 312/338-1522 (fax), frca@frca.org (e-mail), www.frca.org (web).

The opinions expressed in the FRCA *Report* are those of the authors; the *Report* strives to include a variety of perspectives from the family support field.

The FRCA *Report* is published quarterly in the public interest by the Family Resource Coalition of America, a tax-exempt, nonprofit organization. Membership in the Coalition includes a subscription to the FRCA *Report*. Readers are encouraged to copy and share its content; we ask you to credit the Family Resource Coalition of America as the original source of information.

BEST COPY AVAILABLE

In This Issue

Across the country, family support programs and health care providers are forging partnerships to ensure that the comprehensive needs of families are met. Both fields need to engage in these partnerships and in the debate over how best to provide for the health of our nation's families because the realities of the health care system touch families every day and play a large role in family well-being.

The practitioners, physicians, and researchers who contributed to this issue provide examples of how the family support and health care fields are inextricably linked. You'll read of how family support programs are partnering with pediatricians and other health care providers to share resources and set up continuums of care so that the care families receive is comprehensive and flexible.

You'll find examples of how traditional family support services are producing positive health outcomes, as well as examples of programs that are building a new model for healthy communities—a model that engages residents and public health departments in partnerships to promote overall health in communities.

You'll meet programs that are addressing the barriers that families face in accessing health care—barriers such as difficult Medicaid enrollment processes, lack of transportation to health centers, language differences, and practices among providers that deter use.

You'll also find models for implementing health care policy using family support approaches, which are helping families adjust to the changes in health care policy brought on by welfare reform and the shift to managed care.

The imperative for collaboration encompasses more than practice and policy. The social conditions such as poverty, child abuse, substance abuse, and teen pregnancy that family support attempts to mitigate cannot be remedied without cooperation between family support and health care practitioners. All have significant health outcomes that can that reduce the ability of parenting classes, support groups, after-school activities, and other key family support activities to make a difference. All affect families' functioning in ways that reduce their ability to access health care.

The most compelling reason for forging new partnerships is that ultimately these two fields have the same comprehensive and prevention-oriented goal: families and communities that are physically, mentally, and emotionally healthy.

Contents

Family Support and the Emerging Health System 5
Terrance Keenan

Social and Economic Issues Affecting Health—
A Research-Based Argument for Family Support 11
Edward Schor

Improving Access to Health Care

How Your Program Can Help Get Coverage for Children 20
Donna Cohen Ross

HMOs, MediCAL, and Bureaucracy—
How My Program Helps Families 21
Interview with Jorge Lara

What Families With Chronic Illness Need 16
Interview with parent Laura Evans

Linking Pediatricians with Family Support

Pediatricians as Family Support Partners 7
Calvin Sia, Liz Osterhus, and Carol Pandak

Linking Pediatric Care with Family Support—
How One Center Does It 8
Brian T. Conner

Families as Health Care Partners

Parent to Parent—Help for Parents and Professionals 15
Connie Ginsberg

Mothers Mentor Teens as Paraprofessionals 24
Erin Lillie

How I Got Involved in Allocating Health Care Funds 11
Interview with parent Deb Niedfeldt

Public Policy to Promote Healthy Families

How States Can Remove Barriers to Health Care 26
Mary Brecht Carpenter and Laura Kavanagh

CHIP of Virginia—A State Network Links Family Support
with Health Care Services for the Young 17
Angie Francis

State Health Dollars Fund Family Support in Oklahoma 26
Rachel L. Cole

Building Healthy Communities

Montana Coalition Promotes Health and Quality of Life 12
Julia DeLapp

Families Train Health Care Professionals
in Family-Centered Practice 29

Alaska Nursing Students Forge
Community Partnerships 23
Tina DeLapp

Asian Americans Get Culturally Supportive Care
in Denver 21

Resource File 30

Book Review
*Everyone's Children: A Pediatrician's Story
of an Inner-City Practice* 33

Featured Web Page
Partnership for a Drug-Free America 34

Family Portrait 35

Letters to FRCA

Dear FRCA,

We returned [from the FRCA national conference] with a myriad of ideas from the various seminars, workshops, and from the other professionals that we met. . . . This month our family center was the recipient of a HUD Best Practice Award as an organization that helps homeless families in Portland move out of homelessness and into self-sufficiency. We would like to present a workshop at the next [FRCA] national conference to share our ideas with other agencies. Would you please send me information?

Jacqueline M. Carignan
Social Services Division, Family Services
City of Portland, Maine

Congratulations! We'll send you our call for workshop and seminar proposals next spring. Our next national conference will take place April 25–29, 2000, in Chicago.

Dear FRCA,

I appreciated your listing in the resource section of *Report*, Vol. 17, No. 1. Following is a more accurate description of the work that we do.

The Chapin Hall Center for Children at the University of Chicago is a research and development center addressing policies, practices, and programs affecting children and families and the communities in which they live. Chapin Hall's four principal research areas are: children's services, covering the problems that threaten children and the services systems designed to address them; primary supports, concerning the resources in communities that enhance the development and well-being of all children; community building, focusing on the development, documentation, and evaluation of community-building initiatives; and schools' connections, examining the relationships among schools and the other settings in which children learn.

Sincerely,
Jeff Hackett, Editor and Writer
The Chapin Hall Center for Children
at the University of Chicago

How Are We Doing?
A Program Self-Assessment Toolkit for the Family Support Field

Your program works hard to serve and support families every day. But how can you measure your success against all that the family support principles have to offer—and make a plan for improvement?

FRCA has a new tool to help. *How Are We Doing?* gives specific benchmarks to help your program enact the principles of family support every day. With detailed checklists; tools for gathering information from parents, staff, board members, funders, and others; step-by-step instructions; and a computer diskette, this hands-on tool kit gives you the resources to assess:

- Governance
- Outreach/Engaging Families
- Programs and Activities
- Parent Education and Child Development
- Working One-on-One with Families
- Relationships with the Community
- Center Environment
- Home Visiting
- Staff Roles and Capacities
- Monitoring and Evaluation

To order, send $24.95 (members) or $32.50 (non-members) plus $5.00 for shipping and handling to:

FRCA
20 N. Wacker Drive, Ste. 1100
Chicago, IL 60606

Bulk discounts available. Call 312/338-0900.

Call for Submissions

FRCA is creating new ways to share your work with others in the field—including new columns in our quarterly magazine and special areas on our new web site.

We're looking for:

- Articles of 500–2000 words
- Letters to FRCA
- Short book reviews related to family support
- Original art work (drawings work best)
- Photographs of your program in action

Our upcoming issues will contain special focuses on:

- Family involvement and family leadership
- Adoption and foster families
- Schools
- Parent Education

Send us your quality articles on these or any topics that affect families. We welcome your success stories, first-person experiences, tips on specific practices that work, ideas on how programs can strengthen and support families, and anything else you think others in the family support field would be interested in.

All written material should be submitted on a PC-formatted disk and in hard copy. Make sure to include a brief biographical statement, your name, address, phone and fax numbers, and e-mail and web addresses. Authors receive several free copies of the publications in which their articles appear, additional copies at a discount, and gift certificates to use toward FRCA membership and publications. Fees for professional-quality art and photos can be negotiated.

Send to:

Editor, FRCA *Report*
FRCA
20 N. Wacker Drive
Ste. 1100
Chicago, IL 60606
E-mail: jackie.lalley@frca.org
Web: www.frca.org
Fax: 312/338-1522

Moonlight as One of Our Authors!

5
BEST COPY AVAILABLE

Family Support and the Emerging Health System

by Terrance Keenan

The defining objective of family support is to strengthen the capacity of parents to nurture and care for their children. The expression of this objective in practice has exceptional congruence with contemporary formulations in health and health care, and family support principles could well emerge as a major template in shaping the future directions of health policy.

Recognition that successful parenting and family functioning provide the most dependable assurance for the successful growth and development of children is beginning to kindle new concepts and priorities within the domain of health. This phenomenon is attributable, in part, to recent laboratory evidence of the decisive role of the parent-child relationship in infant-toddler brain development. Another factor that helps explain the new salience of family dynamics in health-sector thinking consists of the results of several longitudinal studies showing that affirmative parent-child engagement in the early months and years of life produces positive and enduring health outcomes for children.

The major impact on health and health care concepts arising from these findings from biomedical and behavioral-science research relate to the promise they offer to health-risk prevention. Investigators and practitioners in public health and in personal care services have witnessed appalling increases in exposure to harm among America's children and youth. These threats include physical and mental abuse and deprivation; sexually transmitted disease, including HIV infection; teenage pregnancy and child bearing; addiction to alcohol, tobacco, and illegal drugs; and the pervasive risk of violent injury.

These hazards are prompting those in the health professions to redefine the boundaries of their domains and to engage with such issues in their practices. Medicine, nursing, and public health all are involved. There is considerable consensus that the treatment of children and youth who are victimized by these problems poses an urgent challenge and that effective therapies need to be developed, tested, and implemented. Valid clinical protocols for children confronting such harms are few. Homeless pregnant teens involved in substance abuse constitute a grievous and all-too-common example.

Family Support Offers Strategies

There is also agreement that the strategy of choice for reducing the prevalence of these problems is to prevent their occurrence. As noted, research in brain development and longitudinal studies, including randomized trials, of interventions that affect the quality of parent-child interactions (e.g., home visiting) are elucidating the risk factors underlying these behaviors. The importance of such research for developing strategies in health is that it provides an evidence-based foundation for successful prevention. At the very least, it is now a tenable hypothesis that parent-child bonding can avert threats to the health and safety of children and youth. The qualities of trust, social competence, and self-esteem that children acquire through parental nurture are prime factors that make them less vulnerable to health-risk behaviors.

Family support principles could well emerge as a major template in shaping the future directions of health policy.

The question before the health field is how to act on the evidence at hand and on the claims that it supports. In short, what can the field do in terms of policy and practice to ensure affirmative parent-child interaction and bonding? It is here that the knowledge, insight, and experience of family support programs come into play. They offer the health sector two unique advantages for exercising its special expertise.

Principles and Practices in Place

The first is a tested set of principles and practices for working with children and families. In this respect, family support concepts such as the primacy of competent parenting have a close affinity with progressive thinking in such fields as pediatrics, family medicine, and community and public health nursing. No intrinsic intellectual barrier prevents the health sector from enhancing its influence on family life through alliances with family support. This is beginning to occur in a number of ways, for example, through interdisciplinary research and training at university health sciences centers with strong programs in child and family development (such as Chicago, Cornell, Yale, North Carolina), and through statewide, cross-agency training systems for front-line staff (such as those in place in New York state).

Yet, despite their conceptual affinity, the intellectual distance between research, education, and practice in the health area and in the field of family support is very large. For example, in the discipline of health services research, there are few, if any, studies of the effects of family support services on access to health care. This research gap has occurred at a time of substantial public and private investments in family support programs. The reason for the obscurity of family support programs in health service scholarship and related policy thinking rests, in part, in the origins of family support as a grass-roots community movement. It takes time for academicians and policy theorists to catch up with reality.

Structures Add to Solutions

The second unique advantage that family support programs present the health field consists in the emergence of a large new local and regional structure for implementing the goals of family and community health. This structure consists primarily of some three thousand local family support centers located in schools, churches, family service centers, community health centers, housing projects and other neighborhood sites. These centers are the first line of family support. They combine home-based services (e.g., home visiting) with center-based programs (e.g., day care) in a mix of activities designed to help parents discover and realize their strengths and function as successful caregivers.

Models of Collaboration Between Fields

Health and health care are major concerns of many local family support programs. In most cases, programs provide off-site referrals to established health care providers to address the health needs of the families they serve. However, some programs, including the Greenwood Community Center in South Carolina (p. 8) and the First Baptist Community Development Center in New Brunswick, New Jersey, are the principal health providers for the families they serve. Most family support programs offer education and counseling in personal health practices, reproductive health, maternal and newborn care, and child development. Particular emphasis is given to enhancing parents' capacity to successfully face the challenge of securing health care for their families. Resource Mothers program (p. 24) and the international Parent to Parent program (South Carolina's branch is highlighted on p. 15) provide examples of programs that support families as they attempt to successfully utilize health services.

The opportunities that family support centers open to the health professions for expanding their interface with families are immense. These centers enable physicians, nurses, and public-health professionals to reach families where they live—in the privacy of their homes and within the boundaries of their neighborhoods. Moreover, local centers are joining forces in organized regional networks for such common purposes as staff training. States, counties, and municipalities across the country are constituting these new bodies as legal authorities for the management of funds designated for family-helping services. This means that new helping systems are emerging through which the health sector can exert broad influence and leadership in improving the health status of America's families.

Once again, leaders in health policy and practice are not responding as robustly as they might to the advantages family support is creating for them. Infant mortality, for example, or the tragic scale of child abuse and neglect could almost certainly be reduced through a more vigorous emphasis on health in the new community-based institutional structure being built by family support programs.

Physicians, nurses, and public-health professionals throughout the country have become advocates and participants in the family support movement and have been quick to recognize its congruence with the goals of community health. State public-health officials, in particular, have been in the vanguard of integrating health concepts and resources into the work of family support sites and systems. This issue of FRCA *Report* highlights efforts in two states—Montana (p. 12) and Oklahoma (p. 26)—to integrate family support principles and services into the policy of these states' departments of public health.

A Need for Common Vision

What appears to be lacking is a compelling vision of the family and of its functions as the central locus of the health enterprise. Understanding is there, certainly—particularly in the development sciences—but it has not yet achieved sufficient momentum to become a driving force. Disincentives to envisioning and cre-ating a more energetic symbiosis between health care and family support include the emergence of managed care. The productivity expectations governing medical practice curtail the time physicians in family-centered practice can devote to parent education. Still, this practice need can be addressed through nursing, especially home nursing, or through such innovations as the use of special staff trained in infant-child development (as, for example, in the Healthy Steps program of the Common-wealth Fund).

The most powerful evidence for the benefits of family support arises from scientific inquiry. Health care professionals should be encouraged to seek out that evidence and integrate it into their practice.

Indeed, such innovation is a reflection of the progress being made in the developmental sciences. Symbiosis between health care and family support is emerging among disparate disciplines as a unifying theme governing understanding of biological endowment, behavioral function, and social relationships.

Pursuit of the disciplines relating to child development in the health sector may seem a far cry from its more deliberate and systemic participation in family life and family support. Family support concepts, after all, have their roots in a community movement, not in the cloistered world of research. Yet, it is also true that movements require evidence of their value if they are to be sustained. The most powerful
evidence for the benefits of family support arises from scientific inquiry. As members of science-based disciplines, health care professionals should be encouraged to seek out that evidence and to integrate it into their day-to-day practice.True strength arises from the collaboration of health care professionals, each of whom brings unique discipline-based knowledge to the challenges encountered in family support programs.

Sadly, revenue sources are likely to limit funding and reimbursement to interventions that have been recognized in the field as standards for practice. They are likely to view creative strategies to improve health and family functioning as "nice ideas" or as experiments rather than as critical for successful health outcomes. It is critical that family support workers involve health care providers in collaborative networks designed to improve family health and functioning. Family support practitioners will be effective in achieving their ends if they raise the standard, so that interdisciplinary collaboration toward the application of empirical evidence in family health care and support becomes the standard for practice—rather than merely a collection of isolated examples of best practices.

Terrance Keenan is Special Program Consultant of the Robert Wood Johnson Foundation and is Program Officer for the STATES (State Technical Assistance and Training for Effective Systems) Initiative of FRCA, which is funded by the foundation. The Robert Wood Johnson Foundation is located at College Road East, P.O. Box 2316, Princeton NJ 08543-2316.

Pediatricians as Family Support Partners

by Calvin Sia, Liz Osterhus, and Carol Pandak

Photo by Andrea R. Asanza courtesy CHIP of Virginia

The health care needs of children and families are changing. The advent of improved vaccines, hygiene, sanitation, and public health care practices has led to a decreased emphasis on the treatment of diseases and an increased emphasis on other factors, such as poverty, deteriorating physical environment, changing family structures, and other social and psychological factors. Children who are potentially victims of this "new morbidity" are those who are environmentally at risk, developmentally delayed, biologically at risk, and who have behavioral problems. The challenge of pediatrics today is to respond to these changes and ensure that children of the new morbidity have access to a medical home. This is the specific mission of two programs at the American Academy of Pediatrics: the Community Access to Child Health (CATCH) Program and the Medical Home Program for Children with Special Needs (MHPCSN).

How have primary care pediatricians faced these changes? What has evolved over the years in caring for these children at risk?

A Paradigm Shift in Pediatrics

More than 20 years ago in Hawaii, a plan was developed to ensure that the social, emotional, and nonmedical needs of the child and family were addressed at the same time as the child's medical needs. Called the "Child Health Plan," it noted that the young child is most vulnerable and has the most special needs in the first several years of life, which if not met can result in less-than-optimal development or permanent damage.

To address these early needs, the plan called for designing an integrated system of care that focuses on the well-being of the child within the context of the family. It called for the implementation of the concept that every child should have a medical home that provides primary health care services that are comprehensive in addressing the medical and nonmedical needs of the child and family within their own community.

This perspective of the child and family within the context of their own community amounted to a paradigm shift in the practice of pediatrics. Now emphasis was being placed on prevention, early intervention, and the role of the community in addressing child health needs, as opposed to diagnosis and treatment. This paradigm shift recognized that:

- The multiple and pervasive nature of risk factors challenging families require comprehensive solutions and integrated programs.
- Families should be the center of the service delivery system designed to serve them.
- Every child should have access to a medical home.

Training Programs Spread Preventive Focus

With support from the federal Maternal and Child Health Bureau (MCHB), a training program titled The Pediatrician and the New Morbidity was completed in 1989 in Hawaii and disseminated to select sites nationally. This program taught pediatric residents and practicing pediatricians the importance of integrating services for the benefit of families and how to go about ensuring that all children in their practices,

particularly those with special needs, had access to a medical home.

Likewise, in 1989 the Robert Wood Johnson Foundation granted five-year support for a new initiative, the CATCH Program, to provide training and technical assistance to engage the active involvement of pediatricians in community child health initiatives based on the new morbidity.

Emphasizing the importance of early intervention and partnering with families, The Pediatrician and the New Morbidity program states the following:

"[As a primary care pediatrician] you should be skilled in the use of standardized screening tools [and] you should use parents as a valuable resource in determining a child's capabilities . . . A comprehensive approach to family needs will provide a more successful intervention . . . You can advocate for the entire family by assessing a family's strengths and weaknesses and making sure these are considered in intervention plans."

By the end of 1993, the American Academy of Pediatrics accepted a grant from MCHB to continue to disseminate the message of this curriculum by updating the program with information about changes in the health care environment and by developing educational and advocacy materials that respond to the changing needs of families and practitioners. At the Academy, the project became known as the Medical Home Program for Children with Special Needs. Just two years later in 1995, the CATCH Program became an official program of the Academy.

Every child should have a medical home that addresses the medical and non-medical needs of the child and family within their own community.

The Present: Increased Awareness Among Pediatricians

Currently, the goals of the MHPCSN are to increase pediatricians' awareness of the need to provide a medical home to children with special needs and to help pediatricians address barriers to delivering care to these children by providing appropriate training and resources. In 1992, the Academy published—and in 1997 reaffirmed—a policy statement that included the following:

"The medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known

The Greenwood Community Children's Center

Pediatric Services Are Hub in Family Support

by Brian T. Conner

Doctors and nurses in Greenwood, South Carolina, are working with social workers, librarians, teachers, and others to create a network of support for families that has as its hub pediatricians—a resource commonly accessed by families.

The founders of the Greenwood Community Children's Center call the place where a family gets health care its "medical home," and believe that health care is one of many built-in community assets that, when interconnected, can create a holistic approach to helping parents raise healthy children. The center links pediatric medical care with family support services, and is committed to providing a stable, professional medical home for the children of the greater Greenwood area, including those who are medically indigent or have special needs. It is devoted to building a community of children who are healthy and ready to learn.

The Greenwood Community Children's Center also addresses needs not met by the traditional services of a pediatric medical practice, such as care and education to prevent and treat violence and drug use—sometimes in the context of the children's own families.

The Greenwood Community Children's Center operates under three basic tenets:

- The first three years of life (including the prenatal period) are critical to the optimal development of a child.
- The medical home is a natural contact point for children and families during this critical period.
- Collaborating with existing community efforts and resources will maximize effectiveness and reduce or avoid duplication.

How Providers Become Partners

Founded in January 1997, the Greenwood Community Children's Center has spent its first year and a half nurturing community partnerships to link with parenting education and support, home visiting teams, quality childcare, literacy promotion, and other educational programs designed to enhance the quality of life for all children. The center collaborates with agencies such as the Greenwood County Health Department, the Department of Social Services, public and private schools, churches, and many other public and private family support organizations.

New Staff Position Builds a Bridge

The Greenwood Community Children's Center began by collaborating with the Bowers-Rodgers Home for Abused Children, an organization that wanted to do more to prevent child abuse. Together the two created a Parenting/Abuse Prevention Coordinator position. This staff person develops parents' support groups, resource materials, and classes, including PARENTS (Parenting Abilities Reinforced through Education, Nurturing, Training and Support) classes in infant massage, communicating with one's children,

9 BEST COPY AVAILABLE

to the child and family and should be able to develop a relationship of mutual responsibility and trust with them."

More broadly, the CATCH Program provides training, technical assistance, networking, and grant opportunities for pediatricians and other health care clinicians who are working in their own communities to improve access to health care for all children.

Through the MHPCSN and the CATCH Program, the Academy has increased public and professional awareness of the medical home concept by publishing and disseminating educational and advocacy materials through public and private agencies, parents' organizations, children's hospitals, child advocacy organizations nationally, and community-based groups. Most notably, the Academy is working with Family Voices, the National Association of Children's Hospitals and Related Institutions, and Shriners Hospitals for Children to update the training program that was first developed in Hawaii. This interdisciplinary training program educates parents, physicians, and other health care providers on how to negotiate the current health care environment to ensure that children with special needs have access to all the medical and ancillary services they require. Each component of the training program is designed for presentation by a team of a parents and a pediatrician and/or other health care professional. On managed care, the program advises:

- Physicians should form a network of contracts among other physicians in the community to ensure continuity of care.
- Physicians should explore how managed care organizations handle home health care and other ancillary services (and where appropriate advocate for access to needed services).

This updated training program continues to be pilot tested in 1998 and will be available for national distribution in late spring 1999.

nutrition, reducing sibling rivalry, and discipline.

The coordinator also is working with the Greenwood County Library and the Greenwood Parenting Collaborative to develop a parenting resource center in the library and a directory of parenting services on the internet. "Parenting isn't always easy, but all parents can learn effective parenting skills that will help reduce the stresses of parenthood," she says.

Parents Get One-Stop Support

Another collaboration allows eligible families to access public assistance when they visit the center for family support services and programs. Normally, families have to visit a Greenwood County Health Department office to obtain WIC (Women, Infants, and Children) services and FSS (Family Support Services). But now, a registered nurse works on site at the center, saving families a trip and increasing the likelihood that they will go to obtain services. Those eligible for WIC, for example, can obtain health assessment, referral, nutritional education, and supplemental food.

Home Visiting

The center offers home visiting and training of parent paraprofessionals through its New Beginnings program. The program coordinator trains volunteers to conduct home visits with first-time parents, starting in the third trimester of pregnancy and continuing through six months after the birth of the child. The volunteers provide emotional support, education, and information for new parents.

In addition, the registered nurse who administers WIC services and FSS visits the homes of newborns to assess mothers and infants, provide information on their health, and provide family support services to families who have children with serious medical conditions and/or significant lifestyle concerns that may negatively impact their children's health.

Literacy Partnership

Through the Reach Out and Read program, pediatricians discuss with parents the importance of reading to their children beginning at birth during regular check-ups. The parents get free, age-appropriate books for each child from six months to five years of age. The program promotes language skills, learning, and school readiness for all children by giving parents information they wouldn't have without collaboration among pediatricians, librarians, and others. It is an extension of Born to Read, a collaboration among the Greenwood County Library, Self Memorial Hospital, and several other area agencies.

School-Linked Health Care and Support on the Horizon

A project currently being planned would create a school health clinic to serve both as the medical home for children without access to a physician and as the hub for other neighborhood-based family support programs and services. A collaborative called the East End Neighborhood Program is planning the clinic, and it includes the Greenwood Community Children's Center, Greenwood School District 50, East End Elementary School, Self Memorial Hospital, the Bowers-Rodgers Home for Abused Children, the Building Peaceful Communities Committee, other agencies, and representatives from the school neighborhood.

Brian T. Conner, RN, MHA, is Administrator of the Greenwood Community Children's Center, 410 Epting Avenue, Greenwood, SC 29646, 864/941-8199 (phone), 864/941-8198 (fax), conner@greenwood.net (e-mail).

BEST COPY AVAILABLE

BEST COPY AVAILABLE

A Need for Acceptance

The challenge of this training program and other initiatives that promote the medical home concept is gaining acceptance by third-party payers such as managed care organizations. The Academy has partnered with parents' groups and children's hospitals to document the importance of providing and receiving adequate reimbursement for services such as early intervention and care coordination that benefit children and their families. The Academy recently published The Medical Home Checklist, a tool that itemizes the services that children with special needs require of a medical home. This checklist serves as a self-evaluation tool for managed care administrators and as an advocacy tool for pediatricians. Items in the checklist would require that:

- Families of children with special needs have access to a choice of pediatric medical subspecialists and pediatric surgical specialists.
- The plan has a system in place to assist pediatricians in coordinating medical services with those health and related services offered by the schools and other community-based programs.
- Family support services are provided, including: health education, counseling/support groups, transportation, home visiting, respite care, assistance with transitions, parent-to-parent support, and coordination of care.

To bolster the interest in the checklist and other efforts to promote the importance of the medical home concept, evidence is being gathered through parent satisfaction surveys, physician practice assessments, and outcomes studies.

Access in the Future

The effort to ensure that children have access to a medical home is gaining momentum on a daily basis. For example, the Academy is planning the second CATCH National meeting for April 15–16, 1999, which will address a wide variety of access to child health issues at the community level. Likewise, through the joint initiatives of the Academy, children's hospitals, and parent organizations nationally, increased emphasis is being placed on integrating medical and nonmedical services for the benefit of families as well as to reduce costs.

The effort to ensure that children have access to a medical home is gaining momentum daily.

There is an increased interest in providing preventive services and in enhancing families' strengths rather than simply treating their weaknesses. In a similar vein, there is increased interest in identifying community assets as well as community needs. The importance of early intervention and early education, essential components of a medical home, is gaining recognition.

As the definition of children with special needs evolves, and as the health care environment undergoes change, the Academy continues to respond to these changes with appropriate educational and advocacy materials that benefit all children and their families. The Academy firmly believes in the attainment by all infants, children, adolescents, and young adults of their full potential for physical, mental, emotional, and social health, for children are our most enduring and vulnerable legacy.

Calvin Sia, M.D., is Clinical Professor of Pediatrics at the University of Hawaii School of Medicine and has been a primary care pediatric practitioner in Honolulu for almost 40 years. He can be reached at 656 Paikau Street, Honolulu HI 96816-4406, 808/737-4770 (phone), 808/528-2376 (fax), calsia@pol.net (e-mail).

Liz Osterhus, M.A., is Program Manager of the American Academy of Pediatrics and has experience working with children and families at community-based mental health centers. She can be reached at Medical Home Program for Children with Special Needs, American Academy of Pediatrics, 141 Northwest Point Blvd, Elk Grove Village IL 60007-1098, 847/981-7621 (phone), 847/228-5097 (fax), osterhus@aap.org (e-mail).

Carol Pandak, Ed.D., is Program Manager for the Community Access to Child Health (CATCH) Program of the American Academy of Pediatrics and has experience working on both national and international child health issues. She can be reached at the American Academy of Pediatrics, 141 Northwest Point Blvd, Elk Grove Village IL 60007, 847/9524903 (phone), 847/228-5097 (fax), cpandak@aap.org (e-mail).

Notes

Pediatrics 90 (5)

Developing Communality
Family-Centered Programs to Improve Children's Health and Well-Being

Edward L. Schor

As the nation engages in a major restructuring of societal responsibilities, it is timely and appropriate to consider the impact of social structures on health in general and children's health in particular.[1] Medical care makes only a modest contribution to children's health status. The primary determinants of children's health are social and originate or are experienced within the context of their families. Children's health and well-being is directly related, in turn, to their own life circumstances, social supports, and status in the economic and social hierarchies in which they live.

In the United States, the degree of engagement of families with one another and with the civic and social organizations that shape their lives is declining, and so is their opportunity for support within their communities. Families are losing their sense of belonging to a community—communality—and with it they are losing both real and perceived access to social support and a sense of coherence to their lives. This is especially troublesome for poor families who have greater need for such supports to carry on day to day. When families are poor, their daily lives, including their interactions and relationships, are colored by poverty, and families' functioning is challenged if not diminished. Only by addressing root causes of the social isolation and disengagement of families from the broader resources of society can the functioning and thus the health of children, especially poor children, be improved and sustained.

One need only look within the United States for evidence of the importance of social factors to children's health. Despite living in the country with the world's highest per capita expenditure for health care, many children in the United States are not faring as well as might be expected, particularly regarding health outcomes. The United States compares unfavorably to almost all other countries with comparably developed economies in terms of rates of low birth weight and of infant and postneonatal mortality. Similarly, rates of child abuse, teenage pregnancy, unintentional injuries, and teenage suicide and homicide are higher in the United States than in most other developed countries, and disproportionately so among poor children and youths. Further, trends in rates of child behavior problems, youth homicide, child abuse, pediatric HIV infection, teenage pregnancy, teenage drug use, and limitations of activity associated with chronic illness are going in the wrong direction. These trends are punctuated by a 180% increase in suicide by children of ages 5 through 14 since 1979. All of these problems share a common characteristic: they

Families Speak Out on Health Care

Asserting Our Families' Health Care Needs
How I Got Involved In Allocating My State's Resources

Interview with Deb Niedfeldt

My 10-year-old son David was born 10 weeks prematurely. For the first five and one-half months of his life, he was in Saint Marys Hospital at the Mayo Medical Center. During that time, he had lung damage and had been on a respirator for five to six weeks. When his lungs collapsed he had to have chest tubes inserted on five occasions. David also has been diagnosed with autism.

The hospital staff and administrators were pretty good, but mistakes were also made. For example, David had low tolerance to sodium, but they were flushing his feeding tube with salt water. Another time, the oral gastric feeding tube was not taped down and got moved up near the opening to his lungs. At one point during David's care, the doctor said that he would probably get better care at home.

It was scary. For the first several weeks I was in turmoil and didn't spend time thinking about the doctor. I didn't even know who the primary doctor was. It was a challenge, because the Mayo Medical Center is a teaching facility and the residents are always changing. I believe in helping train residents, but as a parent, I reached a point where I got assertive. I decided that except for non-invasive procedures, David didn't need to be practiced on—it was more than I could bear to watch. The only doctors and staff I would let touch my child were those who were experienced. The hospital respected my choice.

Parents have a real responsibility with children. Some parents won't leave their children alone at the hospital, and they take turns watching them in shifts. Some of the nurses are unbelievable. They took charge and knew before the alarms would go off that my son was in trouble. David used to get almost 24-hour a day nursing care at home. We had some great home-care nurses that we placed great trust in.

As a consultant for MN*TAFS (Minnesota Technical Assistance for Family Support), I travel statewide and am involved with the development of family support with early intervention dollars. I worked with other parents and our senator to draft legislation to get the state to look at what statewide services were needed for children with autism and their families. I coordinate the Family Liaison Project, which is a family support program at Arc Olmsted County. We provide information, referral services, and parent-to-parent mentoring to families who have children with disabilities. We also organize social gatherings and put out newsletters.

Our family is trying to survive this. It took a lot to keep our family healthy. When the opportunity came for a statewide system of technical assistance to local family support committees, I knew what family support meant to me. It is crucial. There is no one way to support a family. Family support needs to be tailored for each family.

BEST COPY AVAILABLE

are not principally health problems—*they are social problems with health consequences*.

The very high value people place on traditional family life (e.g., Gallup Poll, April 7, 1991) has contributed to the increasing but unfair belief that the failure and breakdown of American families are to blame for these social problems. That conclusion overlooks the fact that families exist within a larger society and that social factors exert powerful influence on families' functioning and thus on children's health and well-being . . .

Consequences of Family Changes

Changes in families' structure and mothers' roles have had important consequences for families' functioning and children's life experiences and outcomes. Three of these consequences, only one of which is economic, are especially problematic—income poverty, decreased parental supervision of children, and time poverty.

Economic Consequences

The increase in female-headed households, the low wages available to most women, and the limited hours for work available to a household head with dependent children, coupled with lack of support from absent or estranged fathers, results in more mothers and children being poor. Nearly half of the increase in child poverty rates since 1980 can be attributed to changing family structure. The median family income for female-headed households with children, about $13,500, is less than a third of that of a married couple with one or more children.

Supervisory Consequences

Parents' decreasing ability to monitor their children, the second consequence of recent changes in the family, arises from the need for both parents or for the sole parent to work. When parents work, someone else needs to supervise their children. Fully 48% of children under age 3 and 54% of children under age 6 are cared for by someone other than their parents, and the quality of much of that care has been seriously questioned.

For school-age children, non-parental supervision may mean pre- and after-school care programs, or, for too many so-called latchkey children, no supervision at all until a parent gets home from work. In the United States, about 7% of children aged 5 through 13 and about 15% of children aged 5 through 17 are without adult supervision after school, and self-care is somewhat more common in single-mother households. Unsupervised children are more likely to undertake risk behaviors (i.e., alcohol, tobacco, and other drug use), to be depressed, and to perform poorly at school. These predilections for risk vary with parents' knowledge of their children's whereabouts, with the amount of time children are in self-care, and with other developmental and sociodemographic factors.

Time Consequences

Both poverty and parental employment, separately or combined, can deprive children and their parents of adequate and good-quality time together and create a new kind of poverty—time poverty. Potential parental time (total time minus time in paid work) has declined significantly over the past several decades. This time decrease is strongly related to employed mothers' decreased availability to their preschool-aged children. Lacking material resources such as washing machines, automobiles, and other conveniences such as easy access to supermarkets and health care that make daily chores less time consuming, some poor parents are especially short on time for their families.

Notably, parents report that the portion of time with children that is most likely to be short-changed is time "having fun". Mothers' feelings that they have "the right amount of time" with their children decrease as the number of hours they work each week increases. A national survey of adults in 1991 found that 59% believed that the amount of time children have with

Montana Communities Get State Support for Healthy Collaborations

by Julia DeLapp

Montanans are looking at health in a new way, with a wider lens that brings the whole quality of life of the community, the family, and the individual to bear in determining residents' well-being. The state's Healthy Communities Coalition supports collaborative local health promotion efforts by conducting statewide information campaigns, providing continuing education programs, giving on-site technical assistance, and developing and disseminating publications.

The Healthy Communities Coalition was founded in 1996 on the desire to enhance the quality of life of all Montana citizens. Those in communities who want to collaborate to improve health are getting help from the coalition's coordinated system of education, training, technical assistance, and networking.

Broad Involvement Means Better Health

The Healthy Communities Coalition is a collaborative effort that includes broad representation:

- State government
- Blue Cross/Blue Shield of Montana
- Montana Hospital Association
- Montana Medical Association
- Schools
- Community hospitals
- Clergy
- Montana Community Foundation
- Public health care providers
- Businesses

According to Lynda Blades, public health education specialist with Montana's Department of Public Health and Human Services, Healthy Communities is "not just another state program"; its community-driven nature means it is based on the specific needs of local residents.

Training is one of the major components of the initiative, covering mostly youth issues, asset-mapping, community assessment, and choosing indicators of success. The state provides workshops throughout the state and will soon be offering interactive video conferences. The state also helps guide local coalitions through planning processes that ask participants to define their vision of a healthy community. The local coalitions then discuss the steps needed to achieve that vision.

Each community defines its own geo-

their parents is less than it was 10 years earlier. However, it is not clear that children either benefit or are harmed by maternal employment per se. Children's outcomes reflect the interaction of a great number of biological, psychological, and social factors. Whether and why their mothers work is only one set of contributing factors.

Socioeconomic Status and Child Health

Both theory and a variety of research endeavors support the idea that poverty has its effects on children's health through its tendency to:

- Reduce parents' personal resources
- Isolate families from sources of social support

Further evidence for the social determination of child health comes from large-scale studies, where the relationship between socioeconomic status and health has been investigated. Poverty and the associated conditions of low levels of educational attainment and low occupational status understandably have an effect as adverse on children's health as they do on family functioning. Poverty is the best predictor of poor health outcomes for children, yet the mechanisms through which poverty operates to impair health remain a puzzle. The high death rates of children on welfare and their higher rates of chronic health problems and disabilities may be related to poor families' more limited access to health care. However, the notion that access to care is the sole or even primary explanation for the disparity in health between the poor and the non-poor is unfounded.

The Socioeconomic Gradient

In England and Wales, where universal health insurance is well-established and fiscal access to care is assured for the poor and non-poor, children born into the highest social class, Class I, have a markedly lower rate of neonatal mortality than do infants born into the lowest social class, Class V (432 vs. 663 of 100,000 live births—ratio 1.5:1). The same pattern is even more pronounced for the rates at which children die during the first year of life (241 vs. 584 of 100,000 live births—ratio 2.4:1). By almost all measures, health improves systematically, in a step-wise fashion, with increases in social class, however social class is measured. This gradient is a consistent finding for a wide variety of health measures for children and adults. A gradient is present not only for such diverse measures of child health as nutritional status, rates of emotional problems and learning disabilities, problems with growth and development, and reported ratings of general health status.

Taking Steps: Social Capital and Family Support

What can be done to respond to the striking changes in the life circumstances of the average family and in the diminished opportunities to improve their quality of life? One step toward reversing the trend toward social inequality and promoting social advancement in the United States, most unlikely in the present political climate, is the adoption of economic policies that support income redistribution. A second, and perhaps more feasible strategy is to focus on the "social" end of socioeconomic disparity and address the fundamental lack of a sense of communality and mutual interdependence in society. The existence of income inequality, the rise of homeless people on our streets, and opinion polls indicating a diminishing sense of public responsibility for the needy, all signal erosion of a core social value, the commitment of Americans to one another. This is a major impediment to improving society and takes its greatest toll in diminished quality of life, including health, for poor families. What must precede social development and the improvement of health and well-being is not only economic betterment but also the enhancement of social capital. New enterprise will succeed best when it is located where there are strong social ties and a sense of community.

Social capital, like human and physical

graphic boundaries and its own definition of health. Communities' decision to form these coalitions and to receive technical assistance from the state springs from the desire to have healthy, well-adapted families and youth. As a result of this broad approach to health, communities have adopted a comprehensive range of services, including more traditional health-oriented services such as teen pregnancy programs, nutrition programs, sliding-scale fees for health clinics, placing pediatric nurses in schools, immunization information to parents, and medication assistance for the underinsured, as well as promotional activities that indirectly influence health outcomes. Such activities have included:

- Parenting workshops
- Building new playgrounds
- Addressing job-development issues
- Initiatives to save open space
- Tutoring and after-school programs
- Literacy programs
- Teen theater
- Youth violence and juvenile justice projects
- Increasing access to childcare
- Providing affordable home ownership and low interest rehab loans

Organic Solutions

The goal of Montana's Healthy Communities Coalition is to improve overall health through community involvement. This collaborative, proactive approach enables communities to "get to root causes of problems," explains Meldrum. The solutions that communities create by working together are not "band-aid" solutions.

"Communities have the power to address their problems by identifying and using their own assets and resources," Meldrum explains. "They do not have to rely solely on state and federal government or physicians to ensure healthy families. Healthy Communities enables them to network with other local initiatives and learn how others in Montana have changed things to improve the health of citizens."

MHCC is part of the Coalition for Healthier Cities and Communities, a national effort to sustain healthy community efforts. Based in Chicago, the Coalition supports state and local efforts across the country to involve communities in promoting health, and serves as a unified, national voice on policy issues related to healthy communities. For more information about the national Coalition for Healthier Cities and Communities, contact Brooke Rosman at 312/442-2365 or visit the web site at www.healthycommunities.org.

For more information, contact Lynda Blades, M.P.H., Montana Department of Public Health and Human Services, 1400 Broadway Avenue, Cogswell Building, A-206, Helena, MT 59620, 406/444-7824 (phone) 406/444-1861 (fax).

Julia DeLapp is Family Support Associate at FRCA.

BEST COPY AVAILABLE

BEST COPY AVAILABLE

capital, is productive in that it makes possible the achievement of certain ends that would otherwise not be attainable. Unlike other types of capital, however, social capital is the product of social exchange. It rests on the presence of social networks, communities of people who know one another and whose relationships are characterized by norms and by mutual trust and obligation. While some may feel that material success and social development rest on economic well-being, the opposite is equally and perhaps more true. The existence of social capital has been shown to precede economic and social development.

Adolescents attending parochial schools, for example, have lower drop-out rates even than adolescents in secular private schools, presumably because their parents' lives overlap in multiple spheres (e.g., through the school their children attend and the church to which they belong). Social capital is greater for such families than for those who participate in only one rather than two institutions. In the face of poverty and socioeconomic inequality, children's health and quality of life are likely to improve when their parents have access to social capital—when the feel they belong to a community—and, thus supported, are able to function better in their child-rearing roles.

What can professionals in communities do to create social capital for families and children, especially those experiencing economic deprivation? To borrow from the environment movement, "Think globally and act locally." In this case, thinking "globally" means formulating and operating from a philosophy of human relationships and citizenship that promotes building communality—creating a sense of community within neighborhoods, towns, and the nation. Acting "locally" means linking families to sources of social support—material, instrumental, and emotional—within their communities.

Family Social Support

Local action to create social capital can be guided by the extensive experience of communities that have developed family support programs. These programs take many forms, but all provide the support that assures that families have time together and have the resources and guidance to make full use of that time to nurture relationships between spouses and with children. It is central to family support programs that they help families feel as though they are part of a network of caring and mutual obligation. To provide such support means offering services that are family-centered and that link expectations and goals with tangible means to achieve them; services that protect, nurture, motivate, structure, mediate, teach, and enable; and services that act as a psychological safety net for families to falter without falling.

A large number of public- and private-sector community-based programs have been and continue to be established, programs that provide social support in the form of information, emotional support, feedback and guidance, and practical assistance to families. Social institutions and community organizations have begun to offer a variety of family services that may substitute for or assist families. Home visiting, early screening and referral, parent support, parenting education, and drop-in play are programs commonly found in communities. Schools provide after-school programs for children whose parents cannot be at home when classes end and school-based health services to assist children to receive timely health care and health counseling. Curricula have expanded to include value-laden topics such as conflict resolution, sex education, and community service, topics that previously were the nearly exclusive domain of parents. Employers offer a menu of family benefits such as flexible work hours, shared jobs, and child-care. Government programs such as welfare, Head Start, and Medicaid have supported poor families with children, although their intended and actual role in recent years has been much debated.

In addition, some communities and states have begun efforts to meld funding streams, collaborate across disciplinary and bureaucratic lines, and develop collaborative and, it is hoped, integrated community-based programs. The Healthy Start Programs funded by the US Department of Health and Human Services subscribe to the philosophy of collaboration and cities such as Rochester, NY, are trying to develop comprehensive, coordinated, and integrated services. More than 50 national organizations joined to draft a document outlining the principles of integrated, community-based, school-linked programs.

The recent trend to adopt outcome-based accountability for social programs is likely to reinforce the decision to provide integrated, community-based models of service delivery. However, while these steps toward collaboration and integration are reason for optimism, substantial inertia must be overcome before they move from being community-based to community-focused.

Conclusion

The recommendation to "think globally" to create a sense of community and "act locally" by developing and maintaining family support programs may seem a long distance from the individual health problems of children and the role of child health professionals. But the quality of the lives of children and families, and professionals' ability to improve their health and well-being, is intimately tied to the nature of civic society and the availability of social capital.

Several scholars who have identified the characteristics of successful interventions for children have been left with the question, Why have we made so little progress applying what is known? This paper argues that many of the most vexing health problems of children and adolescents are symptoms that have their origin not in biologic processes but rather in the economic and social inequalities between classes. Those inequalities create not just material deprivation but a poverty of spirit. That poverty rests on a disparity of perceived self-worth and a dependency on too distant social institutions to define that worth and to provide opportunities to participate as members of a civic society. Certainly, at a national level, greater social and economic equality is an obtainable goal. If class disparities in child health are to be reduced, this must be the goal toward which social policy is directed. By promoting policies that foster communality, and by working within local communities to support families in their child-rearing functions, progress can be made. The first step toward achieving more equal status rests on the actions of individuals, especially professionals in work roles and as participants in their communities. While the establishment of a sense of communality can be facilitated by political action, its ultimate success rests on personal initiative and behavior.

Edward L. Schor is Medical Director, Iowa Department of Public Health, Division and Community Health, Lucas State Office Building, and is also Director, Center for Health Policy, Iowa Department of Public Health, 321 East 12th Street, 3rd Floor, Des Moines, IA 50319-0075, 515/281-4912 (phone), 515/242-6384 (fax).

Notes

With permission from the New York Academy of Medicine, this article is adapted from Schor EL (1995). Developing communities, family-centered programs to improve children's health and well-being. *Bulletin of the New York Academy of Medicine* 72:413-44.

Parent to Parent Model Helps Families Cope With Disability

by Connie Ginsberg

Families coping with disability or chronic illness face many challenges: in addition to the typical demands of family life, they must find their way through a maze of social and medical services; learn a new language of medical, legal, financial and special-education acronyms; and help the family member deal with physical pain and day-to-day challenges. They may live in relative in isolation because friends and extended family have distanced themselves.

These parents often say that their first choice for someone to provide support and guidance is another parent in similar circumstances. Parent to Parent programs worldwide take parents' wishes to heart. Approximately 50,000 parents of children with special needs have been matched with others like them who are trained in active listening, feelings of loss and grief, coping, and managing stress.

Called Support Parents, most of the parents volunteer their time simply because they believe in the importance of sharing their experiences, emotional support, and relevant information with other parents through the one-to-one match. Since their beginnings in Omaha, Nebraska, in the early 1970s, these locally based programs have grown to number more than 500, with at least one program in every state. Besides one-on-one support, the programs organize support groups, family socials, guest lecturing, and hosting of medical students in families' homes. One well developed application of the model is taking place in South Carolina's Family Connection.

South Carolina: Parent to Parent In Action

In 1989, a South Carolina mother of a child with Down syndrome made a presentation on the Parent to Parent model at a hearing sponsored by the local disability and special needs board. Her five-minute talk spurred two days of phone calls from parents and professionals who wanted a way for families of children who have special needs to gather and provide mutual support. This effort blossomed into a statewide application of the Parent to Parent model that is now Family Connection of South Carolina, a nonprofit, grassroots, parent-driven organization. Its mission is to provide parent-to-parent support that strengthens families and to increase awareness about persons with disabilities and chronic illnesses.

Family Connection is an organization in which parents and professionals place their confidence. It is committed to reaching out to all families, and this year at the International Parent to Parent Conference in Atlanta, Ga., it received the Pierson Award for best practice in reaching underserved populations. The organization made 1000 Parent to Parent matches in 1997.

Key among its efforts is the Family Partner Program. Family Partners, employees of Family Connection, are supported through a contract with South Carolina's early intervention program for ages birth to three, which in turn is federally funded through the Individuals with Disabilities Education Act (IDEA). They provide frequent support to families who have infants and toddlers, meeting with parents at medical or therapy appointments and in home visits on a regular basis for several months. Family Partners visit parents while their infants are in neonatal intensive care and at home, when the rounds of therapists and medical specialists can be especially stressful. They help parents adjust to their unexpected role as parents of children with special needs, providing tips on communicating with professionals and suggesting ways to reduce stress.

Approximately 50,000 parents of children with special needs have been matched with others like them who are trained in active listening, loss and grief, coping, and managing stress.

Another Family Connection effort is the Minority Outreach Initiative, which forms support groups in Columbia's public housing communities, where families cope not only with disabilities but with poverty. More than 200 families have become involved in the four-year-old initiative, and eight parents have completed Support Parent Training and are leading their groups' efforts. Many children who had fallen through the cracks of the service system now are receiving care, due to parents' increased knowledge of and the support they receive in accessing services.

Parents Say It Works— And Give Back to Others

Parents who have participated in these Family Connection programs often want to give back to those who helped them. Many choose to participate in 12 hours of training and become supporting parents themselves. Thus, the network grows: nearly 400 parents have been trained. As referred parents adjust and find their many strengths, they become their children's first and best teachers and develop as advocates for their child and for other children and families. Many supporting parents have become advocates and leaders in the disabilities movement in their local communities as well as in state and national advocacy and Parent to Parent programs.

Parents who receive family-to-family support and assurance identify their supporting parent as a reliable ally. They say that Parent to Parent support increases their acceptance of their situation and sense of being able to cope. Interviews with parents suggest that the support Parent to Parent offers is unique and probably could not come from any other source. From 1994 to 1996, researchers from the Hood Center at the Dartmouth-Hitchcock Medical Center, the University of North Carolina, and the Beach Center on Families and Disability at the University of Kansas undertook a national study to determine the efficacy of Parent to Parent support. Four hundred people in parent to parent organizations in New Hampshire, Vermont, North Carolina, South Carolina, and Kansas participated. Parents worked with researchers to design the study, write the grant application, and carry out this important research, which was directed by Dr. George Singer, now at the University of California at Santa Barbara, Calif. The study showed that more than 80 percent of the parents found Parent to Parent to be helpful. Of the interviewed parents participating in Family Connection's Family Partner Program, 90 percent found Parent to Parent to

be helpful.

Family Connection of South Carolina has grown through strategic planning and a broad base of public and private funding, and the efficacy study and independent evaluations of the Family Partner Program are used to explain the value of Parent to Parent. But while research and evaluation are important, the parents say it best: "My support parent has been the silver lining to my cloud. She has helped me understand the doctor process and has helped me be the best mom I can be. She has been there for me at all hours by phone and has always seemed to know when I needed to talk." This unique form of support for parents of family members with disabilities can play a central role in any comprehensive family support system.

Connie Ginsberg is a parent of two children with special needs. She is Executive Director of Family Connection of South Carolina, Inc., 2712 Middleburg Drive, Suite 103-B, Columbia, SC 29204. 803/252-0914, connieg@mindspring.com (e-mail).

For information about Parent to Parent, contact Betsy Santelli, Director of Parent to Parent Program Support at the Beach Center for Families and Disability, 3111 Haworth Hall, University of Kansas, Lawrence, KS 66045, 785/ 864-7600.

Families Speak Out on Health Care

Coping With Chronic Illness

One Family's Challenges—and How Family Support Helps

Interview with Laura Evans

What health problems are you and your family coping with?

I have had multiple sclerosis for 10 years. I also had a lung disorder and went to the Mayo clinic for treatment. Now it's in remission. I see an M.D. every six months and a neurologist every three months. Both doctors have followed my health for years.

My daughter, Bronte Grace, was premature. I take her to the University of Minnesota to see a cardiologist, an orthopedist, and a genetics specialist. She [receives health care from] the state and has full coverage, including prescriptions, until she is two. Right now she is 14 months old. I'm worried about what I will do when she turns two.

Do you have health insurance?

I have Medicare, but it doesn't pay for much. Each month, I have a spend-down of $147 plus a Medicare payment that takes $55 out of my social security. Even with this, not everything is covered. All of this is making me crazy. I'm going to take my daughter to a joint specialist in July to see if she requires surgery on her knees. Then we have to wait.

What kind of support is helpful to parents dealing with the health care system?

My doctors have accepted consignment on Medicare. My eye doctor, neurologist, and internist are terrific. They told me about the Share program, where you can get prescription drugs through the manufacturer.

There is so much stress involved in locating insurance and doing the paperwork. One time it took five and a half months to process a claim with the state. I finally got the spend-down, but it's up to [me] to do it. The stress made my multiple sclerosis worse, and I have a little one to tend to. But it could be worse than this—I could have nothing.

What role does family support play in your life?

When I go to the hospital, a family support center in the hospital helps, because it's hard to find a sitter. The receptionist at my primary doctor's office has a free daycare center. There are three receptionists, and one watches the children while the others deal with the patients and answer the phones. It would be good to have more support like that, but somebody would have to have my problems to appreciate this. I need a sitter only when I need to go to the doctor, because I stay at home with my child.

What would improve the health care system?

The workers should be more helpful, the costs should be lower, and the terms should be easier to understand. Insurance should pay for preventive care. A system like the Canadian system would be good. I have been dissatisfied with all the health care systems I have dealt with—with their workers, costs, and their terms. Their stipulations read like tax forms. Getting prescriptions is so expensive it's like getting a hot dog at the airport for seven dollars. Recently, I had to pay $80 for an antibiotic.

Because I have a pre-existing condition, insurance companies wouldn't cover me. It's not fair. People get sick when they are young. Medicare will not pay for a mammogram. Insurance companies won't pay for preventative care, but they will pay when you get cancer.

Laura Evans

Bronte and Laura Evans

Laura Evans is a photographer. She has worked in photographic equipment sales, photographed events, and had her work published. She still takes pictures of children and photographs weddings professionally when she is healthy.

BEST COPY AVAILABLE

CHIP of Virginia is Statewide Solution to Family Health Barriers

by Angie Francis

We know that poverty, low educational attainment, and lack of access to health care add up to lifelong poor health. It follows that if we are to improve life for young children in need, we must build new systems of health care services that:

- Improve access to care
- Take a two-generation approach
- Support the educational development of both children and their parents
- Support family self-sufficiency

Programs that link family support with health care services offer solutions to problems common in today's heath care systems. As the CHIP of Virginia network shows, these solutions can be especially effective for families who are hard to reach with traditional services. Part of the federal Children's Health Insurance Program (see page 22), CHIP of Virginia puts home visiting teams to work serving hard-to-reach families.

The System—and How Family Support Can Help

Many pressures on today's health care systems build barriers to providing effective services for young children. The drive toward profitability and greater productivity in health service delivery means that families with young children who need extra support often fall through the cracks. The growing educational and cultural gap between health care providers and families in need often leaves both families and providers frustrated.

Family support—with its mission to develop prevention-oriented, family-centered, community-based care through parent education, parent support, life-skills training, and information and referral—can provide a set of tools for serving young children that is greatly needed by health systems. Family support strategies include providing culturally relevant services and hiring and training staff from diverse communities. Staff members who come from the community can be extremely effective in building bridges between families and health care providers.

The CHIP of Virginia Network

The target of CHIP's services are children birth to age six from families with incomes of up to 150 percent of the federal poverty level who are experiencing barriers to care. These families are referred to CHIP from many points in the community. CHIP home visiting teams comprised of a public or community health nurse and home visitors with community experience work with families to address the multiple barriers to effective care. A team of one nurse and two home visitors serve a caseload of about 150 children.

The CHIP home visiting team is able to change the relationship between a hard-to-reach family and the health care system. The staff meets with the family to develop a health care plan for each child, focusing on prevention, including well-child care, immunizations, and dental care. The family receives education about the importance of preventive care and of keeping appointments. The staff also helps the family plan transportation, prepare for appointments, and think about questions to ask or information to share with the provider. They also provide the family with needed support in recommended follow-up. During the first few months in CHIP, families and providers are guided to form a collaborative relationship based on positive incentives.

Linking family support with case management makes it possible to address the multiple barriers to access and effective utilization of services. The team can assist a family with everything from Medicaid eligibility and enrollment to managing the complexities of specialty providers and services needed to serve a child with special health care needs. The CHIP team also provides a home safety assessment and assistance in correcting unsafe conditions.

The goals of CHIP of Virginia—which now has eleven sites serving 28 Virginia localities and 4,300 children in 2,400 families—are improved child health and improved family self-sufficiency. Program evaluation demonstrates:

- Increased immunization rates (to over 90% of program participants)
- Effective linking of mothers and children with a "medical home" in the private sector
- Increased employment of mothers

Why Invest In "Extras"?

Given the success of programs like CHIP of Virginia, why isn't more being done to link family support services with health care services for young children? Perhaps one reason is that adding services that do not fit cleanly into reimbursement categories, and are perhaps delivered by a nontraditional provider or seen as "extra," goes against market forces that encourage controlling costs by controlling utilization of services. However, we know that preventive health services are essential to the health of young children and that ensuring them, even if this requires additional services, is in fact cost effective.

The lack of effective systems for assuring preventive and primary care in today's health care market has an impact on the bottom line. In Virginia, four of the five most frequent reasons for the hospitalization of children under nine years old are conditions that usually do not result in hospitalization if managed effectively in a primary care setting: asthma, pneumonia, gastroenteritis, and dehydration. (The fifth reason for hospitalization is unintentional injury.) We can no longer afford to spend our health care dollars in this way. But how can we redirect these dollars to prevention and primary care?

The opportunities of expanded children's health insurance provide incentives to reach out to children eligible for insurance through Medicaid. Maturing managed care markets also provide opportunities for managed care organizations (MCOs) to look beyond enrollment to building systems of care for special populations. The greatest challenges are in financing these essential services for young children.

Starting on a Small Scale

The CHIP of Virginia network and other programs that have effectively linked family support with health care services are struggling to develop the contracting expertise necessary to work effectively

with MCOs and integrated health systems. MCOs and integrated health systems are searching for effective strategies to manage costs, to improve quality, and to build better systems of care. It would be of great benefit to children, families, health systems, and communities to find innovative financing strategies, to build new partnerships, and to pilot contracts to find effective links for these services. Successful small-scale programs must be integrated into financing and delivery systems, enabling them to grow and to improve the health of communities.

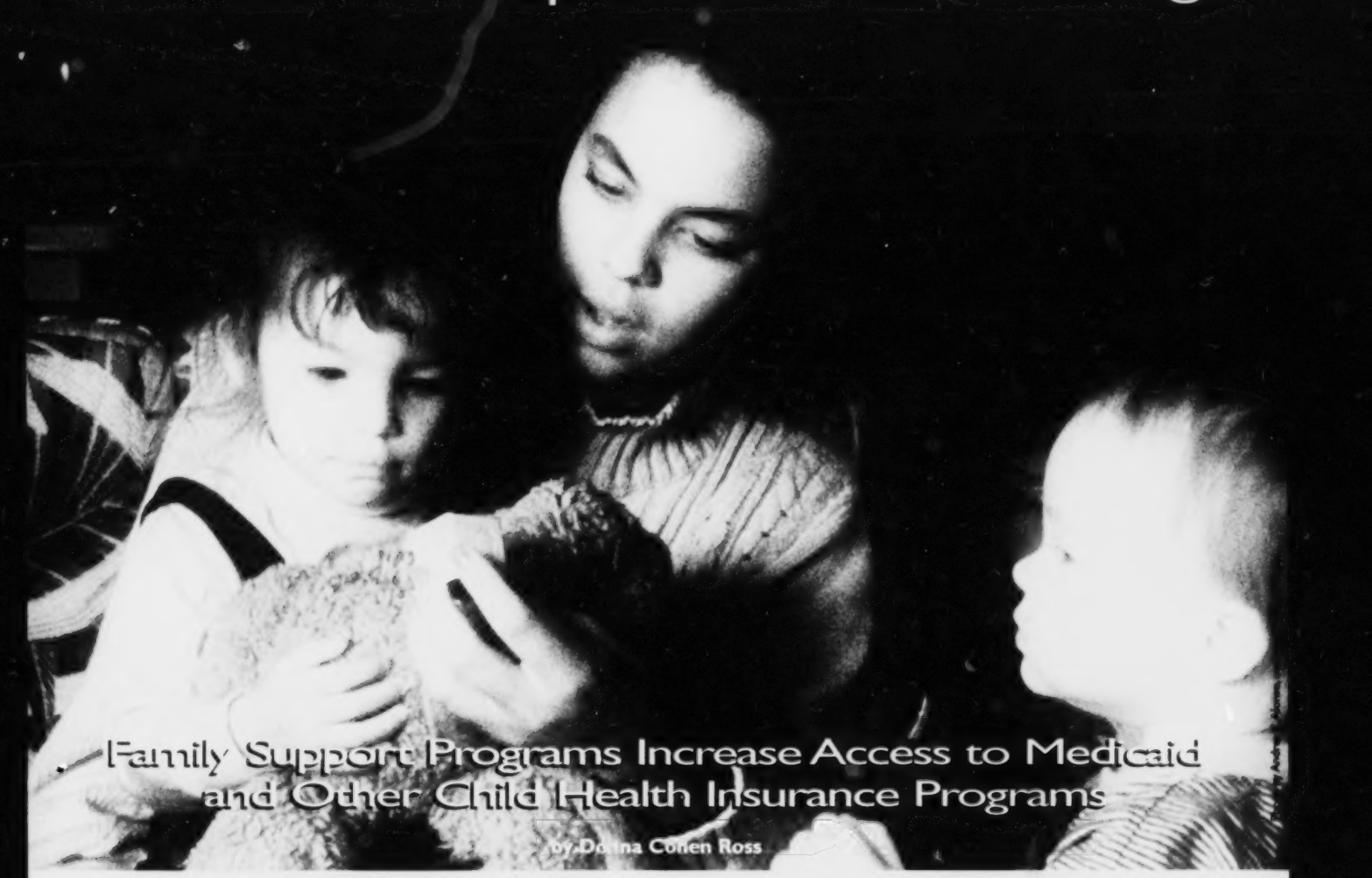
If we build the family's capacity to use health care services effectively, then we can support families in building safe nurturing environments so that their children can grow up healthy and ready to learn. Policymakers, health systems, and managed care organizations must discover ways to solve the financing challenges to integrating the systems of care and of reimbursement so that today's young children and their families can become the building blocks for tomorrow's healthy communities.

Angie S. Francis is Executive Director of CHIP of Virginia, 145 W. Campbell Avenue, Suite 440, Roanoke, VA, 24011, 540/345-9370, 540/342-4161 (fax), chipasf@aol.com (e-mail).

Photos by Andres R. Alonso, courtesy CHIP of Virginia

19

How Can We Help Children Get Coverage?



Family Support Programs Increase Access to Medicaid and Other Child Health Insurance Programs

by Donna Cohen Ross

One of the most important first steps any family support program can take is to help families obtain health insurance for their children. Parents often rely on family support professionals whom they know and trust for advice and help in finding health care for their children. But obtaining medical services, especially preventive care, can be difficult—or next to impossible—without insurance.

Working parents who earn low wages—and who are not likely to have health insurance through their jobs—need to know that their young children may be eligible for health insurance through Medicaid or other child health insurance programs. More than 11 million children in the U.S. have no health insurance, mostly because their families can't afford it. But, for about 4.7 million of these children—more than 40 percent—comprehensive coverage is available for free already through the Medicaid program. And, coverage for many children who aren't eligible for Medicaid may soon be available for free or at low cost through Medicaid expansions or new child health insurance programs financed by the new federal child health block grant.

Many families with eligible children don't realize their children qualify for health coverage. Others may know about the programs but do not know how to apply. For some, a complicated application process or being required to go to a social service office during business hours to apply may present significant barriers.

Early childhood programs around the country are pioneering strategies to inform families about the availability of health insurance and also helping them get their children enrolled. Some states have taken advantage of Medicaid administrative funds to contract with early childhood programs for these services. Some of the Children's Health Insurance Program money states receive also can be used to cover the cost of outreach activities (see sidebar, page 22). Family Support programs can learn from these experiences as they make efforts to get involved in outreach activities.

Here are 12 ways your program can help:

1. **Inform families about the availability of free and low-cost health insurance.** Display posters and distribute flyers or other materials any place where families and children gather. Post information on classroom bulletin boards and distribute information at parent meetings. Send flyers home with children's artwork, lunch menus, and notices about upcoming activities. Don't forget children who are on the waiting list for childcare: chances are, they can get health insurance right away. It is increasingly important to let families know they do not have to be receiving welfare benefits for their children to be eligible for Medicaid. Also, they can apply for Medicaid without having to apply for welfare. If your state has a short, mail-in Medicaid application, keep a supply on hand to give to families. Always provide a checklist of documents that must be submitted with the form.
2. **Make income eligibility screening for Medicaid and other health insurance programs part of the routine.** Income

eligibility for one program can "flag" eligibility for Medicaid if the income guidelines are similar. Once you identify a child likely to be eligible for Medicaid, at a minimum, refer the family to a place where an application can be submitted. Better yet, assist the family in completing a Medicaid application at the same time the family applies for other benefits, such as subsidized childcare, Head Start, WIC, or Child and Adult Care Food Program meals. This will be relatively easy if your state has a simple, mail-in Medicaid application.

3. **Make sure training programs include information about the availability of health insurance for children through Medicaid or other programs.** Many family support programs conduct training of one sort or another. Whether it's health and safety training for classroom staff, in-service training for providers, or parenting classes for parents, there are many opportunities to incorporate information on how families can obtain health insurance.

4. **Work with your state or local Medicaid agency to become a Medicaid outstation, or arrange for Medicaid enrollment workers to visit your center on a regular basis.** States must provide the opportunity for families to apply for Medicaid at sites other than the Medicaid office. To accomplish this, Medicaid eligibility workers may be outstationed at certain hospitals or health clinics. States also can outstation eligibility workers at nontraditional sites such as family support programs. Keep in mind that these eligibility workers can rotate among several locations. Team up with other community based programs in your area to "round out" the worker's itinerary.

   Alternatively, staff of family support programs can be trained to do initial processing of applications, which entails helping families complete the Medicaid application and gather the required documents so that eligibility can be determined by the state agency. States can contract with programs to do this work, and Medicaid administrative funds can help cover the costs.

   Be sure your Medicaid outstation site addresses the needs of applicants in your

Families Speak Out on Health Care

Our System Needs to Change to Cover Families

Interview with Jorge Lara

Does your family have health insurance?

My wife, Rosa, has insurance through her work, but it does not cover any of our five children. My wife wants to pay for insurance to cover me and all the children, but then her whole check would go for health insurance. Two of our children are covered by a program called California Kids. The clinic is six miles away. Immigrants who are not U.S. citizens also qualify. The program was started by wives of sports stars who saw a need in the community. I have one child who is in college and is not covered. It's not fair, risking your life all the time. My other two children are covered by insurance through their jobs.

What is your position on national health care coverage?

I support a national program like they have in Canada. None of the current plans help. HMOs are business-orientated. MediCAL is a bureaucracy. They don't check on you until you have a chronic disease. Money can be saved through preventative medicine, but to save money they try not to give you medicine and procedures.

How do you think HMOs have changed health care?

HMOs are changing health care in a bad and insensitive way. It's a complicated system involving millions of dollars. People are afraid to use services because they are applying for citizenship. They are afraid that if they use the health care services, immigration will find out and it will hinder their application. The system is confusing and the laws are changing all the time. Doctors are caught up in red tape and if you ask questions they get upset.

What can people do to change the system?

I always try to lobby for coverage. Thousands of people in the San Fernando Valley don't have coverage at all. We meet with [politicians and HMO administrators] and tell them what we need, but they don't listen.

What programs does your organization participate in that work to solve some of these problems?

There are programs with the local college and with different government offices that train people in the community to become health promoters by learning about first aide, diseases, public services, and licensing for child care. These people then go out into the community and help deal with health issues. They advocate for and guide families members through the health care system and help with solutions. This is a tool to teach families what to expect from the system. They also teach families not to abuse the system by overusing and/or expending their resources.

Jorge Lara is the Director of the Pacoima Urban Village, 12700 Van Nuys Blvd., #287, Pacoima, CA 91331.

Asian Americans Get Culturally Supportive Care in Denver

The Community Health Leadership Program (CHLP), supported by the Robert Wood Johnson Foundation, named Denver's Sumiko Tanaka Hennessy as one of this year's 10 outstanding individuals changing the shape of health care in America.

As Executive Director of Asian Pacific Development Center (APDC), Hennessy understood that Denver's Asian community, numbering more than 89,000 and comprised of many different ethnic groups, needed a full-service health center with a bilingual staff attuned to cultural nuances. APDC places "community health" in a broad context and offers mental health services, English classes, exercise workshops for older people, substance abuse treatment and HIV/AIDS prevention, domestic violence counseling, vocational training programs for adults and youth, professional translation services, and even a Shiatzu (acupressure) class for the elderly. Preventative health care is dispensed in the patient's language or dialect. APDC serves 2,500 clients annually and has 63 bicultural and bilingual staff.

Hennessy, originally from Yokohama, Japan, overcame language and cultural barriers to become Executive Director of the APDC in 1984. Selected from more than 500 candidates from all over the country, she received $100,000 from CHLP: $95,000 for program support and $5,000 for a personal stipend.

For information on how to nominate a community health leader, contact CHLP, 30 Winter Street, Suite 920, Boston, MA 02108.

BEST COPY AVAILABLE

community. For example, provide childcare so parents can give their attention to completing the application. Offer interpreters for applicants who speak languages other than English. Schedule hours that are convenient for working families, such as early mornings, evenings, or weekends.

Persuade your state to adopt the Presumptive Eligibility Option—and use it to enroll children in Medicaid. Presumptive eligibility, a state Medicaid option established by the Balanced Budget Act of 1997, can be an effective tool for enrolling more children in Medicaid. By bringing the enrollment process into more community-based settings, presumptive eligibility can increase the opportunities for families to obtain health insurance for their children. Another advantage of the new option is that it can help children get prompt attention for their health care needs.

Under the presumptive eligibility option, if a child appears to be eligible for Medicaid based on the family's declaration of its income, he or she can be enrolled on the spot for a temporary period, pending a formal Medicaid eligibility determination. Qualified entities that can make presumptive eligibility determinations include traditional Medicaid providers, such as pediatricians, community clinics, and school-based programs that receive Medicaid reimbursements. States also may authorize WIC programs, Head Start programs and state or local entities that determine eligibility for subsidized child care to presumptively enroll children in Medicaid. The law requires that families complete the formal Medicaid application within a set period of time and family support programs can be instrumental in helping families close this loop.

While some states (Connecticut, Massachusetts, New Hampshire, New Mexico and New York) have decided to establish presumptive eligibility procedures for children, most have not yet done so. In some states the Medicaid agency can make the decision to adopt the option; in other states, legislation may be needed before this can occur.

6. **Conduct Medicaid outreach at special events.** Health fairs, Head Start recruitment day, kindergarten registration, community festivals, or story hour at the library offer opportunities to talk to families about health insurance for their children. Be there—any place, any time families and children are likely to gather.

7. **During home visits, share Medicaid information and assist families in applying for the program.** Home visits present a special opportunity to discuss family health issues. Families may be more relaxed and willing to take the time to learn about Medicaid benefits and complete application forms.

8. **Use a telephone resource line to encourage families to seek information about Medicaid and get children enrolled.** Telephone "helplines" established to help families obtain benefits or services can be enhanced by adding a component that assists families who need health insurance for their children. For example, childcare resource and referral agencies, which help parents find appropriate, affordable childcare, do much of their work over the telephone. During their conversations with parents staff often share information about services other than childcare that families and children need. They can provide information about how to obtain Medicaid or other child health insurance benefits and help families complete simple applications over the telephone. Follow-up calls can be made in a few weeks to ensure that the process has gone smoothly or to give additional help.

9. **Enlist the business community in promoting the Medicaid program.** Urge local merchants who cater to families to let their customers know about the availability of health insurance for children. Successful outreach campaigns have persuaded store owners to tuck flyers into children's shoeboxes, home-delivered pizza boxes, grocery bags, toys, back-to-school notebooks, and book bags. Fast food and family restaurants can print outreach messages on place mats. Utility companies may be willing to insert information in customer bills. Businesses in your community also may have employees with children eligible for Medicaid. Remember that children with private insurance may use Medicaid to cover services not covered by their private plan; also, Medicaid can help make private insurance more affordable for families by assisting with premiums and other cost-sharing.

10. **Partner with schools.** Linking up with your local school or school district is a common-sense, high-impact strategy. First and foremost, schools are where the children are! Schools are often the place where the negative effects of a lack of medical attention are directly felt when teachers detect student performance problems linked with health concerns.

11. **Work with other organizations and agencies to improve outreach and referral systems.** Hospitals, WIC programs, schools, early childhood programs, health clinics, housing programs, food assistance programs, legal services, religious groups, and others can be part of an effort to help children obtain health insurance. Work on ensuring that all child health insurance programs are coordinated and free of administrative barriers.

12. **Don't forget about your own staff.** Many workers in family support have children who are eligible for coverage under Medicaid or other child health insurance programs. Average salaries for these workers tend to be quite low—around $12,000 per year—which means their children are likely to qualify in most states. Post information about child health insurance on staff bulletin boards or insert information into employee paychecks.

Use CHIP to Insure Children in Your State

The Children's Health Insurance Program (CHIP), signed by President Clinton in 1997, allocates $24 billion over five years to states to insure low-income children. Each state that applies and is approved is guaranteed at least $2 million. States may spend the money to insure those who are under 19, are ineligible for Medicaid, and have family income levels at or below twice the current poverty level.

Each state designs and develops its own plan; the program guidelines describe the minimum benefits that states may provide under CHIP. All 50 states have submitted plans, and 41 have been approved. To find out more about the program in your state, contact the U.S. Department of Health and Human Services at 202/619-0257 or visit one of the following web sites at www.hhs.gov or www.hcfa.gov/init/children.htm

Donna Cohen Ross is Director of Outreach for the Center on Budget and Policy Priorities, 820 First Street N.E., Suite 510, Washington DC 20002, 202/408-1080, 202/408-1056 (fax), www.cbpp.org. CBPP conducts Start Healthy, Stay Healthy, a national outreach effort to enlist early childhood programs and community organizations to identify children from low-income working families who may be eligible for Medicaid or other public child health insurance. Contact CBPP for an outreach strategies kit.

BEST COPY AVAILABLE

Nursing Students Help Communities Forge Health Care Solutions

Alaska Students Get Grassroots Training

by Tina DeLapp

In Alaska, nursing students are finding that sewing needles can be as important as hypodermic needles in meeting their communities' health care needs. Students at the University of Alaska are helping and learning from their communities while creating holistic health care solutions as part of their coursework.

One group of eight students worked for 10 weeks with temporary residents of a local shelter for homeless women and their children. For many of the women, sewing was a stress-reducing activity—which the students knew was linked to improved health. The students solicited donations of fabric and sewing machines from stores.

After spending two weeks participating in shelter activities and talking with residents, the students concluded that resources were available to meet the residents' basic needs for shelter, food, and health care, but that using these resources required substantial energy and often created stress. Further, while residents had techniques for relieving stress, some of their techniques—such as sewing—were of limited value or impractical in immediately stressful situations.

After confirming with residents that additional stress management skills were sorely needed, the students devised a three-pronged approach to meet the need. First, they developed a three-lesson stress management course. This included three 15-minute lessons on recognizing stressful situations, ineffective responses to stress, and techniques for defusing stressful situations and preventing similar stress-responses. This curriculum was evaluated, revised, and used again; lesson outlines were left at the shelter so that staff can use them on an as-needed basis in the future.

Second, the students responded to the women who used sewing as a stress reliever by seeking donations of fabric remnants from local fabric stores. Their efforts were more than successful; indeed, one merchant was so impressed with their project that he donated both fabric and two reconditioned sewing machines to the shelter.

The third strategy addressed women's comments that knowing the requirements of a service reduces the stress experienced by those trying to use it. The result was a booklet designed to provide the type of information the women had identified as useful. In addition to listing the names of community resources and describing the services that they provide, the booklet told residents how to access and use them. For example, the reader might be told to have their own and their child's social security numbers handy when calling for an appointment. Or she might be told that all morning appointments were scheduled for 9 am but that she might not be seen until 10 or 11 am; being seen at 9 am might be facilitated by signing in by 8:30. The students raised funds to have 30 copies of the booklet professionally printed and planned to leave these at the shelter along with a master copy on disk that the shelter staff could update and reproduce. They were both surprised and delighted when the printer was so impressed that he printed 100 copies and donated them to the shelter.

The fruits of this 10-week learning experience continued long after the students completed the course, something that is seen consistently with the community nursing projects. Other projects have resulted in support groups for people with hepatitis C, parents of children with cancer, and grandparents raising grandchildren. These support groups are still in place.

Recently students assisted a local church in developing a structure to support parish nursing in a caring community. Pamphlets regarding breast self-examination and annual PAP smears have been translated into Korean and are now distributed by local Korean churches; local physicians and imaging centers share a brochure with information about services and supports available to women recently diagnosed with breast cancer.

All of these projects were possible only with the involvement and support of both local health providers and businesses, all have made positive contributions to community health, and all have lasted long beyond the graduation of the students who spearheaded them.

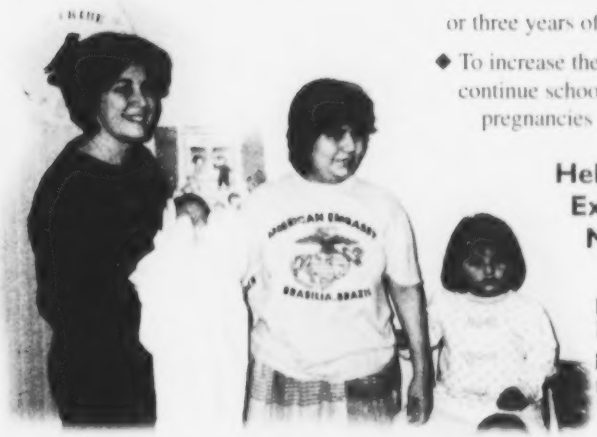
Tina D. DeLapp, RN-C, Ed.D., is professor and director of the School of Nursing at the University of Alaska Anchorage. A member of the nursing faculty since 1975, Dr. DeLapp's current work involves recruitment and retention of Alaska Natives to careers as registered nurses. She can be reached at 3211 Providence Drive, Anchorage, AK 99508-8030. 907/786-4550 (phone).

BEST COPY AVAILABLE

Mentor Moms Reduce Health Risks for Teen Parents & Their Children

Innovative Program Targets Latino Teens

by Erin Lillie



Mentor mother Bunny Latkin and teen mom with second baby (her first born was in El Salvador).

Teen parenthood poses challenges for those seeking to support and strengthen families: Prevention of teen pregnancy obviously is the first step, but teens who do become parents need help developing parenting skills and getting information so that their children are born as healthy as possible—and stay healthy.

One community in Virginia has come up with a strategy to reduce the risks faced by children who are born to teenaged parents: placing experienced parents in the role of mentoring these teens.

The Resource Mothers program of the Fairfax County YMCA was started in 1989 to provide mentoring and advocacy to pregnant and parenting teens in the county. The primary objective of the program is to reduce incidences of low birth weight in babies born to teen mothers. Secondly, the program focuses on providing access to care for the high number of Latino teens who often fear or are unfamiliar with the system and therefore delay seeking the care they need for a healthy pregnancy.

The four main goals of the program are:

- To reduce the number of low birth weight babies
- To reduce the number of infant deaths within the first 12 months of birth
- To reduce the number of girls who enter a second or third pregnancy within two or three years of having a first child
- To increase the number of girls who continue school during and after their pregnancies

Help from an Experienced Mother

Pregnant teens are paired with a Resource Mother, a full-time, paraprofessional community health care worker who is trained and sensitive to the needs of the pregnant adolescent. The Resource Mothers are bilingual, and many of them are from another country and were young mothers themselves. Each Resource Mother is assigned 20 to 25 girls and is responsible for conducting two or three home visits to each girl per week, maintaining phone contact, referring the teens to needed social services, and providing transportation to all appointments.

The Resource Mother also stays with the mother during her appointments to provide emotional support as well as translation and advocacy between the doctor and the teen. After the baby is born, the mentor continues to support the mother until the child is two years old, helping the young mom get and follow through on doctor's appointments for the baby, family planning services, and infant immunizations.

Resource Mothers Provide Whatever It Takes

Although most of the stated goals and objectives of the Resource Mothers program are health-related, director Pat Deninger is quick to point out that other unstated objectives frequently take precedence. As the friendship and trust between the Resource Mother and the teen mother grow, it may become apparent that the teen needs assistance finding mental health services, victim's assistance, housing, drug/alcohol treatment, or an advocate to work with the school system so that she can stay in school.

The Resource Mother supports the teen mom in every capacity necessary and, consequently, the bond between the two often lasts for many years after the teen has left the program.

Statistics Show It Works

Resource Mothers has impressive statistics showing that preventative health care and intensive home visiting are effective and extremely cost-effective. A recent six-month review based on 138 teen participants yielded the following results:

- Ninety-seven percent of babies were born at a healthy birth weight (5lb. 8oz. or higher)
- Ninety-six percent of the teens did not experience a repeat pregnancy
- There were no infant mortalities
- The 86 percent of teens who were enrolled in school at the beginning of the pregnancy stayed in school during pregnancy

These statistics far outshine statistics gathered from the state of Virginia. Additionally, it is estimated that a low-birth weight baby born at Fairfax Hospital stays an average of 26 days at a cost of $1,500 per day. Therefore, every time the Resource Mothers program prevents low birth weight in a baby, it saves the county $39,000 in medical costs, not including the costs that health care and special education cause later.

Over the course of a year, it is estimated that Fairfax County saves $2,000,000 from the prevention of low-birth weight babies. The cost of case management for one teen for a year in the Resource Mothers program is $2,400. In addition, 98 percent of children aged birth to three years who were born to parents mentored by Resource Mothers do not need intervention from the child protective services system.

Resource Mothers claims there is no

magic involved in the program, but magic is what happens when pregnant teens are paired with adults who are nonjudgmental, available, caring, and supportive.

For more information, contact Pat Deninger, Director, Fairfax County Branch, YMCA of Metropolitan Washington, Resource Mothers Program, 2940 Hunter Mill Road, Oakton, VA 22124.

Erin Lillie is an intern with FRCA. She recently obtained her bachelor's degree in social work from Miami University in Oxford, Ohio, and plans on pursuing an MSW in the near future.

Support for Teen Parents

ABOVE LEFT: Teens at clothing swap. Clothes are picked to disguise pregnancy—allowing teens to feel less self-conscious in school.

LEFT: Teens help each other and have fun at clothing swap.

ABOVE: Teen mom and four-month-old baby—born 4 lbs., 2 oz., four weeks early.

Removing Barriers to Health Care for Children

Policies to Ensure All Children Get Health Care

by Mary Brecht Carpenter and Laura Kavanagh

To reduce the number of uninsured children in this country and improve children's health status by providing access to health care, Congress recently created the State Children's Health Insurance Program (CHIP), which states are now implementing. The program encourages states to provide subsidized health insurance to low-income children by either expanding state Medicaid programs or establishing new programs to buy health insurance for children, or through combination of both approaches. This new program builds on the Medicaid expansions for children and other children's health insurance programs that have been implemented over the past decade to reduce the number of uninsured children in this country.

Although these are all welcome and well-intentioned efforts, without effective outreach, they will fail. Simply making health coverage available does not guarantee that all, or even most, eligible children will receive it. No children's health insurance program has been able to insure more than half of the eligible children. In 1994 nearly two-thirds of Medicaid-eligible children who were not receiving cash assistance (which conferred automatic eligibility for Medicaid) failed to enroll in the program. As welfare reform reduces the cash assistance rolls, many more children are likely to become uninsured.

Photo © 1997 Stephen Shames / Matrix

The ASPECTS program in in Honolulu, Hawaii, helps military moms and dads learn parenting skills. Here, a health care professional provides a family with information.

What Are the Barriers?

Although the primary—and crucial—goal of the Medicaid expansions, CHIP, and other health insurance initiatives is to remove financial barriers to health care, children face numerous other barriers to care. Outreach to find and enroll children is the first step, but similar attention must be paid to ensuring that, once they have a Medicaid or insurance card, children actually get the services they need. Barriers to care are numerous, and they emanate from both personal and system issues, including:

- Lack of transportation
- Lack of understanding or denial of the child's health problems

Family Support Is Part of State Health Program in Oklahoma

by Rachel Cole

The state government in Oklahoma has made the link between promoting health and providing social supports for parents, children, and families. State health funds are paying for training, education, and services on stress management, grandparenting, parent-child enrichment, and enhancing self-esteem for parents and other family members, as well as activities to promote community development and community wellness.

The Child Guidance Program of the Oklahoma State Department of Health initially provided educational testing in schools. In 1956, when the program was founded, even educational testing was a unique twist on health services, and was touted as a way to assist Oklahoma families in their "capacity to nurture their children, promote optimal development, and build healthy family relationships."

When its was introduced, the Child Guidance Program was an unprecedented attempt to address the developmental, behavioral, and social factors that influence health outcomes. Now the program includes even more types of support not traditionally

BEST COPY AVAILABLE

- Clinic hours that conflict with work schedules
- No childcare for other children in the family
- Overcrowded clinics with long delays in getting appointments, or long waits in the waiting room, often with more than one child in tow
- Competing family or personal issues and priorities
- Doctors' unwillingness to see Medicaid patients
- Patients' concern that the care received is either unresponsive to their medical needs or interpersonally disrespectful.[2]

Personal Barriers

Personal barriers depend on a family's specific situation and the family's health beliefs, experiences with the health care system, culture, and ability to make it a priority to go to the health care provider. Children targeted by Medicaid and CHIP are typically from lower-income families who face more obstacles in their daily lives than do families with more means. The level of education of a child's mother is an important predictor of well-child visits and is generally lower for low-income children.[3] To be effective, outreach strategies must take into account these and other characteristics of the target population.

System Barriers

Health care system barriers have their source in individual clinics and physician offices, Medicaid policies and procedures, the medical profession, and the capacity and structure of the health care delivery system. Targeted approaches that address specific concerns—like a clinic's hours of operation, a need for improved health education materials, and the availability of childcare on site—can be handled locally and potentially without great expense. Issues such as providers who do not accept Medicaid patients or the maldistribution of pediatricians are much more difficult and require the attention of state and federal officials, provider groups, community leaders in affected areas, and others.

What Works in Ensuring that Children Receive Care

Getting children timely and appropriate health care requires parents who are knowledgeable about their children's health, what their health coverage does and does not pay for, how to make and keep an appointment, how to communicate effectively with providers, and how to follow through with the instructions received. It requires a system that has providers who will see Medicaid and low-income patients; that has reasonably short waiting times for appointments; that is relatively close by, welcoming, friendly, and supportive; that has hours of operation which are responsive to working parents and providers who are available by phone after-hours; that has staff knowledgeable and helpful about other services a child may need; and that provides monitoring and follow-up.

Regardless of the financing mechanism that enables a family to pay for care, the system that they enter should meet these kinds of criteria. The appropriate use of preventive and primary care is a shared goal among the public health profession, Medicaid, managed care plans, community health centers, and others who are part of the health care network used by children. Collaborations between these players can create effective and aggressive strategies to reduce barriers and increase access that will ultimately result in healthier children. To increase their likelihood of success, these collaborations should also include the consumers of care: low-income families with children.

Strategies to Reduce Personal Barriers

- Financial and other incentives to enrollees, such as coupons for free gifts when families use medical services
- Desirable health education classes to teach parents about prenatal care, newborn care, the importance of immunizations, and useful resources
- Public awareness campaigns regarding the importance of preventive health care and where to get it
- Grassroots outreach through home-visiting and community-health advisors to screen family members for health and social services needs, develop a plan of care, directly provide health services, provide linkages to needed services, and educate parents about the importance of preventive health care
- Transportation assistance

Strategies to Reduce System Barriers

The health care system that has developed over the years to serve low-income populations is well known to be fragmented and difficult to negotiate. In areas where low-income families usually live, the capacity of the health care system and infrastructure is limited. Addressing these problems is part and parcel of ensuring that children have access to care once they have an insurance card in hand. Many states and communities have worked to reduce these

considered to be health services. The state legislature regularly has allotted health funds to these programs because, by augmenting medical assistance, they help accomplish the health department's broad mission: "to assure the conditions by which our citizens can be healthy."

Staff of the Department of Health and the Child Guidance Program long ago recognized the preventative benefits of detection and early intervention services on health outcomes. The department's policy became even clearer recently, when the Child Guidance Program staff were merged with the Maternal and Child Health Service, enabling the program to restate its goal of prevention, and to add a focus on families instead of individuals. The program's goals, as articulated in May 1998, are:

- **To improve the quality of family relationships, including parental, parent-child, and sibling; and relationships of family members to their external community and its institutions**
- **To increase parents' abilities to provide appropriate guidance and learning opportunities for children**
- **To improve the capacities of communities to provide support and resources for families to successfully rear their children**

To contact the Child Guidance Program of the Oklahoma State Department of Health's Maternal and Child Health Service, call 405/271-4477.

Rachel L. Cole, an intern at FRCA, is an undergraduate at the University of Chicago studying public policy and economics.

28

BEST COPY AVAILABLE

BEST COPY AVAILABLE

barriers for children and families and thus have experience to draw on as CHIP is implemented and more uninsured children enroll in health plans. For example, states have improved provider participation in Medicaid by streamlining the billing process and raising payment rates. Some states have also been building strong infrastructure in remote rural areas and inner cities where shortages in health care have been noted. Because the vast majority of children with CHIP coverage will be enrolled in some form of managed care, strategies to reduce barriers presented by that system deserve special attention from the states. The following are some effective ideas.

Improve Provider Training

Managed care plans have important roles to play in improving their providers' ability to work with Medicaid and other hard-to-serve groups. They can train providers and others on the frontlines, they can contract with traditional providers, such as community health centers and local health departments who know these populations well, or both. The chief goal of any of these strategies is to ensure that networks include providers who are familiar with the needs of children, particularly low-income children.

Make Clinics, Offices, and Staff User-Friendly

If a mother brings her child in for care and is met with a long wait in a crowded waiting room, is treated with disrespect or disinterest by the front office staff, has nothing with which to entertain the other children whom she brought along because she could not or did not make other arrangements, or is told that she will need to come back because the one doctor is backed up because of an unforeseen emergency, she may leave and never come back. If she tries to get an appointment and cannot make one within a reasonable amount of time, she may not call again. These barriers are specific to a particular clinic and need to be addressed at that level, but they can occur anywhere. To ensure access for children, providers, program managers, and health plans need to be aware of these issues at the point of service and take steps to reduce or eliminate them.

Offer Care Coordination for Children

Although most children are healthy and their health care needs are very basic, some children face chronic conditions, such as asthma or diabetes, that require special attention. Care coordination, also often called case management, can ensure that they get the range of services they need, and it is a valuable aspect of quality care. To reduce inappropriate emergency room use and to prevent asthma-related hospitalizations, health plans have initiated innovative case management programs that at the most basic level include education on asthma triggers, how to manage an attack, and when to go to the doctor. More comprehensive programs also include home assessments for triggers, developing a plan with the primary care physician, and assistance in finding specialty items such as hypoallergenic pillow cases. Several asthma-management programs have shown some promise in reducing emergency room use and in preventing asthma attacks requiring hospitalization.[4]

Care coordination also can be used for children with social, economic, and other risk factors that make it difficult for them to get the health and other services they need. Care coordination is a powerful service-organizing strategy that can surmount the barriers and fragmentation that typically exists between the health and related services that these children need. Care coordinators identify a child's needs, plan what services are necessary, link their clients with those services, educate parents about their child's health condition and needs, and review progress toward goals for the child's care.[5] Medicaid will pay for care coordination, and over half of the states use this strategy for pregnant women and/or for children.[6]

Conclusion

Families, health plans, public health and Medicaid agencies, foundations, policymakers, community organizations, and employers share a common mission of improving access to primary and preventive care for children through the highest-quality, most cost-effective means possible. Outreach is critical to identifying eligible children, facilitating their enrollment in health coverage programs, and ensuring that they have access to a high-quality health home.

Outreach efforts require careful research of the target population's needs and the barriers they face to accessing health care. Strategies must be designed to address these needs and issues, and the strategies must be as flexible and adaptable as needed to reach those who do not respond to initial outreach efforts. Creative partnerships should be forged with community organizations and groups that know the target population and can help link families to care. Information systems must be developed that track the effectiveness of outreach strategies on health access and health outcomes wherever possible. These kinds of concerted, broad-based efforts to devise effective outreach strategies are needed throughout the states so that the promise of health insurance coverage to improve the health of children can be realized.

Adapted from: Carpenter, M.B. & Kavanagh, L.D. (1998). Outreach to Children: Moving from Enrollment to Ensuring Access. *(Arlington, VA: National Center for Education in Maternal and Child Health).*

Mary Brecht Carpenter, R.N., M.P.H., is a senior policy analyst, and Laura Kavanagh, M.P.P., is the director of the Office of Policy Analysis at the National Center for Education in Maternal and Child Health, Georgetown University, 2000 15th Street North, Suite 701, Arlington, VA 22201-2617, 703/524-7802 (phone), 703/524-9335 (fax), www.ncemch.org.

Notes

This article was adapted from Carpenter, M.B. & L.D. Kavanagh (1998). "Outreach to children: Moving from enrollment to ensuring access." (Arlington, Va.: National Center for Education in Maternal and Child Health).

[2] U.S. General Accounting Office. (1987). "Prenatal care: Medicaid recipients and uninsured women receive insufficient care." (Washington, D.C.: U.S. General Accounting Office).

[3] Riportella-Muller, R., et al. (1996). "Barriers to the use of preventive health care services for children." Public Health Reports, 111: 71-77.

[4] Short, P.F. (1992). "Encouraging preventive services for low-income children: the effect of expanding Medicaid." Medical Care, 30.

[5] Moe, E.L., et al. (1992). "Implementation of open airways and educational intervention for children with asthma in an HMO." Journal of Pediatric Health Care, 6: 251-255.

[6] Wissow, L.S., et al. (1988). "Case management and quality assurance to improve care of inner-city children with asthma." American Journal of Diseases of Children, 142: 751-752.

[7] Berkowitz, G., Hafon, N., & Klee, L. (1992). "Improving access to health care: case management for vulnerable children." Social Work in Health Care, 17.

[8] National Governors' Association. (1997). "MCH update: State Medicaid coverage of pregnant women and children." (Washington, D.C.: National Governors' Association).

Families Train Health Care Professionals in Family-Centered Practice

Models for the Family Support Field

by Rachel L. Cole

Families all over the country, especially in the special-needs community, are taking on the role of teacher—helping physicians, nurses, and other health professionals become more responsive to families as they provide health care.

These new parent roles are important because even the most knowledgeable physician will be unable to help a family if he or she is not trained in lowering the family's barriers to service delivery. Families themselves are the best people to teach health care professionals how to address concrete issues such as how to accommodate a parent's difficult work schedule or lack of convenient transportation as well as issues such as cultural difference, socioeconomic stigma, and blame.

Parents Teach Future Providers in Universities

We Care, a child and family advocacy organization in North Carolina, provides a way for families to collaborate with academics to improve service delivery to the special-needs community. With four professors of East Carolina University, parent advocates from We Care team-teach a class called "Interdisciplinary Practice in Services for Children with Serious Emotional Disorders and their Families."

The students come from a variety of disciplines, including social work, nursing, and psychology. Rejecting the traditional model of studying and practicing each service in isolation, the class helps students envision a comprehensive, non-fragmented system of care that meets the needs of the whole family. Parent advocates share with service providers their challenges, such as coping with feeling they are to blame for their children's disorders, and communicating with health care professionals.

By hearing parents talk about these issues, students begin to appreciate the complex issues faced by families and the crucial link between the well-being of a special-needs child and that child's family. The importance of listening to parents is impressed upon students. As advocate Sally Stephens explains, "Parents know kids. They are your experts." The interdisciplinary setting allows health students to see the services they will provide as a part of a continuum of services to ensure the overall wellness of the entire family.

Another academic collaboration is organized by the Family Resource Center at Vanderbilt University Children's Hospital and Family Voices Tennessee. Families who use the resource center volunteer to be on a list of experts in specific areas—for example, ethical issues or the concerns of single-parent families. This list is given to all the professors at Vanderbilt who teach classes related to children with chronic illnesses. Professors call on parents for consultations or class presentations, where they tell stories of their own experiences.

Students begin to appreciate the complex issues faced by families and the crucial link between the well-being of a special-needs child and that child's family.

While the program is still growing in the fields of medicine and child development, parents are widely used resources in the School of Nursing. Dara Howe, director of Family Voices Tennessee, notes that as the benefits of the program become clear, more and more medical school faculty who were hesitant to bring parents into the academic setting are putting aside their initial reservations and using the parent volunteers in their classes. She feels that the family-centered training the students receive will not only benefit the families of the special-needs community, but all families.

Parents Provide In-Service Training

Hawaii Families as Allies, an organization for families of children with emotional disorders, provides workshops to health professionals who already are practicing. Parents give workshops on a variety of topics, all emphasizing the importance of recognizing the impact of emotional disorders on a family and integrating cultural awareness into service delivery. Parents participate both as professional trainers and as attendees, giving feedback during the sessions to help doctors, nurses, and public health officials understand the families they're serving. In addition, case managers attend, helping health professionals understand the larger system of care that families are dealing with.

As families take active roles in promoting family-centered health care, other options for parents as teachers of family-serving professionals become apparent, such as including parents in training social workers and educators. Examples such as We Care, the Family Resource Center at Vanderbilt University Children's Hospital and Family Voices Tennessee, and Hawaii Families as Allies can provide models of how parent involvement in training can bring the family support approach into a variety of fields.

Rachel L. Cole, an intern at FRCA, is an undergraduate student at the University of Chicago studying public policy and economics.

RESOURCE FILE

This resource file is a starting point for finding additional information, publications, and assistance in the area of youth development. It is not a comprehensive list. To be added to future lists, please contact FRCA at 20 N. Wacker Drive, Suite 1100, Chicago, IL 60606.

Publications

Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents

Ed. by Morris Green, M.D., 1994.

This guidebook seeks to answer the challenging question of how childcare professionals can be more effective in disease prevention and health promotion. Detailed information on development is offered with regards to infancy, early childhood, middle childhood, and adolescence.

National Maternal and Child Health Clearinghouse
209 Chain Bridge Road
Vienna, VA 22182-2536
703/821-8955

Children's Health 1996: MEPS (Medical Expenditure Panel Survey) Chartbook No. 1

By Weigers, M., Weinick, R. and J. Cohen, 1998

This chartbook is a collection of data assessing where we stand on three issues related to children's health. The first section looks at the health insurance status of children in the U.S., the second section looks at access to health care with a focus on common sources of care and barriers to care, and the third section looks at the overall health status of children.

Agency for Health Care Policy and Research, Publications Clearinghouse
P.O. Box 8547
Silver Springs, MD 20907-8547
800/358-9295
Publications #: AHCPR98-0008

Families and Health

By William J. Doherty and Thomas L. Campbell, 1998

Part of the SAGE publications' Family Studies text series, this publication looks at the biological dimension of family life. Health care providers are increasingly becoming aware of the link between chronic illnesses such as heart disease and cancer, and family factors such as life-style and social environment. The book is intended to provide an introduction and overview of the family and health field for a multidisciplinary audience.

SAGE Publications, Inc.
2455 Teller Road
Thousand Oaks, CA 91320
805/499-0721

The Future of Children: Critical Health Issues for Children and Youth Vol. 4, No. 3, Winter 1994

By Center for the Future of Children / The David and Lucile Packard Foundation

This collection of articles from the Future of Children series summarizes knowledge and experience in selected areas that are relevant to improving public policies that have an impact on the well-being of children and youth. The recurrent theme in each of the articles is that the family is central to each of the health problems faced by children and youth regardless of the specific issue.

Center for the Future of Children
300 Second Street
Suite 200
Los Altos, CA 94022
650/948-3696

Health Care Reform and Child Welfare: Meeting the Needs of Abused and Neglected Children

By Child Welfare League of America, 1994

In this document, the Child Welfare League of America defines the wide range of health care services needed by children in the child welfare system and therefore the services that should be included in any health care proposal.

Child Welfare League of America
c/o PWD
9050 Junction Drive
P.O. Box 2019
Annapolis Junction, MD 20701-2019
800/407-6273

Healthy People 2000: National Health Promotion and Disease Prevention: Objectives—Full Report, With Commentary

By Public Health Service (DHHS) Office of Disease Prevention and Health Promotion, 1991

Presents the objectives of a national strategy for improving the health of the Nation through prevention of major chronic illnesses, injuries, and infectious diseases. It discusses the health needs of different age groups and special populations, priorities for health promotion and disease prevention, and the commitment of shared responsibility. Also discussed are the objectives of this national health promotion and disease prevention program. A list of the leading agencies in each priority area is included in the appendices.

Office of Disease Prevention and Health Promotion
National Health Information Center
P.O. Box 1133
Washington DC 20012-1133
800/336-4797

Family Matters

Free journal for the children's mental health field edited by a collaboration of organizations nationwide.

Comprehensive Community Mental Health Services for Children and Their Families Program
Deidre Jacobs Barksdale
202/408-9332 (fax)
jacobs@wbgh.com (e-mail)

The Medically Complex Child: The Transition to Home Care

Ed. by Neil J. Hochstadt and Diane M. Yost, 1991

Provides professionals and caretakers working in this field with a comprehensive overview of the most current issues, programs, approaches, and resources available about challenging issues facing families, health care providers, and social services concerning the transition of medically complex children from hospital care to home care. Many pediatric hospitals and child welfare agencies are struggling to develop appropriate techniques, mechanisms, and resources to assist these children and their families. Special emphasis is given to medically complex children entering alternative care settings such as foster care or adoptive care.

Harwood Academic Publishing
Book Orders, PTT
P.O. Box 566
Williston, VT 05495-0080
800/326-8917

So You Want to Start a Community Health Center: A Practical Guide for Starting a Community Health Center

By National Association of Community Health Centers, Inc., 1996

Intended for local communities or health-care organizations that want to explore starting up or converting their operations into a community health center; this practical guide covers community health center basics such as: ensuring broad community support and investment; developing community governance; needs assessment and planning; staffing; establishing a health center organizationally and physically; financial planning; insurance; MIS/data systems and recommendations.

National Association of Community Health Centers
1330 New Hampshire Avenue, N.W.
Washington, D.C. 20036
202/659-8008

Monitoring Medicare HMOs: A Guide to Collecting and Interpreting Available Data.

By Families USA, 1998

The guide covers the following data sources: Health Care Financing Administration (HCFA); performance monitoring reports; HCFA disenrollment reports; state utilization data; medical loss ratio data; HCFA Medicare appeals data; HCFA's Medicare Managed Care Plans Comparison Database; information available from the National Committee for Quality Assurance (NCQA); and other sources. For each data source, the guide will tell you what it is, why it's useful, where you get it, and how to interpret your findings. Step-by-step directions are provided when interpretation of the data requires computation.

Families USA
1334 G Street N.W.
Washington, DC 20005
202/628-3030.

Organizations

Agency for Health Care Policy Research
P.O. Box 8547
Silver Spring, MD 20907-8547
www.ahcpr.gov

Supports research designed to improve the quality of health care, reduce costs, and broaden access to essential services. Programs are designed to bring practical, science-based information to medical practitioners, consumers, and other health care purchasers.

American Academy of Pediatrics
141 Northwest Point Blvd.,
P.O. Box 927
601 13th Street, NW
Elk Grove Village, IL 60009-0927
847/228-5005

Suite 400 North
800/433-9016
Washington, DC 20005
202/347-8600
www.aap.org

Professional membership organization for pediatricians dedicated to the attainment of optimal physical and mental health for all infants, children, adolescents, and young adults. Activities include advocacy for children and youth, public education, research, professional education, membership service, as well as advocacy for pediatricians.

The American Medical Association
515 N. State St.
Chicago, IL 60610
312/464-5000
www.ama-assn.org

A partnership of physicians and their professional associations dedicated to promoting the art and science of medicine and the betterment of public health. Develops and promotes standards in medical practice, research, and education as well as advocates on behalf of patients and physicians. It is primarily a resource for physicians; however, it does provide accurate, timely information on certain topics to program providers and the general public.

California Center for Health Improvement (CCHI)
1321 Garden Highway, Suite 210
Sacramento, CA 95833-9576
916/646-2149 fax: 916/646-2151
www.policymakers.org

Independent, non-profit, prevention-focused health policy center that disseminates objective, accurate, and easily understood information about community health and health-care issues. Program areas include a publications list, public opinion research, and consultation and technical assistance.

Center for the Advancement of Health
2000 Florida Ave., NW, Suite 210
Washington, DC 20009-1231
202/387-2829 fax: 202/387-2857
e-mail: cfah@cfah.org
www.cfah.org

Operates from the perspective that health issues are intimately linked to human attitudes, emotions, thoughts, behaviors, social relations, and economic status. The Center identifies research needs, promotes interdisciplinary research, and gathers, summarizes, and synthesizes findings. Has consumer and professional publications including books, journals, and newsletters.

Center For Health Policy Research
George Washington University
2021 K Street, NW, Suite 800
Washington, DC 20006
202/296-6922 fax: 202/296-0025
www.gwumc.edu/chpr

Conducts research and policy analysis on complex health policy issues. Identifies, monitors, and analyzes emerging issues in federal health law and policy and evaluates the impact that changing federal policies have on states, communities, and the health care system.

The Foundation for Accountability (FACCT)
520 SW Sixth Ave., Suite 700
Portland, OR 97204
503/223-2228 fax: 503/223-4336
www.facct.org

A non-profit organization dedicated to helping Americans make better health care decisions. Creates tools to help people make quality-based decisions, develops consumer-focused quality measures, promotes public education about health care quality, supports efforts to collect quality data, and monitors public policy. Also publishes a quarterly magazine called "Accountability Action" which provides project updates and insights from leaders in consumer-focused quality measurement and accountability.

Families USA Foundation
1334 G Street, NW Third Floor
Washington, DC 20005-3169
202/628-3030 fax: 202/347-2417
www.familiesusa.org

A non-profit, non-partisan organization working at the national, state, and community level to achieve high-quality, affordable health and long-term care for all Americans. Provides technical assistance to state and community-based organizations, produces health policy reports describing the problems facing health care, conducts public information campaigns about the concerns of health care consumers, serves as a consumer clearinghouse for information about the health care system and performs many other functions.

Health Systems Research, Inc.
1200 18th Street, NW Suite 700
Washington, DC 20036
202/828-5100 fax: 202/728-9469
mchneighborhood.igjp.edu/hsr

A health policy and research firm that provides technical assistance to state health agencies in support of their efforts to develop comprehensive systems of care for children and their families. Addresses a range of issues in different states: analyzes alternative strategies for delivering and financing services for high-risk mothers and children under managed care; develops quality assurance standards for children with special health care needs under managed care; designs "wrap-around" benefit packages for high- and at-risk pregnant women and children; conducts community-level systems development training; facilitates strategic planning workshops on new roles for Title V; develops systems development performance indicators; and plans integrated data systems. Website includes written reports on most of their technical assistance projects.

The National Adolescent Health Information Center (NAHIC)
University of California San Francisco
1388 Sutter St., Suite 605-A
San Francisco, CA 94109
415/502-4856 fax: 415/502-4858
www.ucsf.edu/youth
A policy information center which promotes linkages among sectors of the health care system that affect adolescents through the following activities: promotion of collaborative networks, information collection, analysis, and dissemination, research studies, policy analysis, technical assistance, consultation, and continuing education. Also publishes fact sheets and reports on a number of topics related to adolescent health as well as a checklist for planning and evaluating components of adolescent health care.

National Association of County & City Health Officials
1100 17th Street, NW
Second Floor
Washington, DC 20036
202/783-5550 fax: 202/783-1583
www.naccho.org
A membership organization composed of health departments, corporations, associations, universities, individuals, and a number of other organizations interested in public health. Its mission is to improve the health of people and communities by assuring an effective local public health system. Provides education information, research, and technical assistance to local health departments and facilitates networking among local, state, and federal agencies. The association also has an extensive publications list.

National Committee for Quality Assurance
2000 L Street, N.W.
Suite 500
Washington, D.C. 20036
202/955-3500 fax: 202/955-3599
www.ncqa.org
A private, not-for-profit organization dedicated to assessing and reporting on the quality of managed care plans. They provide information that enables purchasers and consumers of managed health care to distinguish among plans based on quality, thereby allowing them to make more informed health care purchasing decisions. This encourages plans to compete based on quality and value, rather than on price and provider network. They have both a system of accreditation (which looks at a health plan's structures and systems) and performance measurement (which looks at results the plan actually achieves).

Physicians for a National Health Program
332 S. Michigan Ave. Suite 500
Chicago, IL 60604
312/554-0382 fax: 312/554-0383
www.pnhp.org
A network of 8,000 physicians and health care workers across the country that support universal access to health care. An advocate for democratically controlled health care reform that embraces social justice and medical need. Activities include: teaching the public how to be effective health care activists, educating physicians and other health care professionals, conducting public research, advising legislators and lobbyists at the state and national level.

Universal Health Care Action Network
2800 Euclid Ave., Suite 520
Cleveland, OH 44115-2418
216/241-8422
800/634-4442 fax: 216/241-8423
www.uhcan.org
A national network of individuals and organizations who believe that health care is a basic human need and should be available to all. Seeks to create nationwide momentum for health care justice through education, outreach, and advocacy. The network is involved at the grassroots level providing "alert" mailings, national and regional conferences, referrals to local health care justice groups, publications, on-line information, library resources, materials, and strategies for public education and technical assistance.

Washington Business Group on Health
777 North Capitol St., NE, Suite 800
Washington, DC 20002
202/408-9320
www.wbgh.org
A national non-profit organization that promotes corporate competitiveness, productivity, and the well-being of American workers and their families. Provides a forum for employers, health coalitions, government, insurers, labor academicians, providers, and consumers to pursue collaborative health policy issues. Keeps members informed through policy briefs, legislative alerts, publications. Represents members' interests through congressional testimony, educational meetings and briefings, and collaborates with other respected health care, policy and business organizations.

On-Line Resources

www.epa.gov/children
In May of 1997, the Office of Children's Health Protection (OCHP) was established out of the EPA in response to President Clinton's Executive Order requiring all federal agencies to assign a high priority to addressing health and safety risks to children. Its mission is to make the protection of children's health a fundamental goal of public health and environmental protection in the United States. The site contains valuable information on children's health research, other federal agencies, children's health publications, and international children's health.

www.brightfutures.org
Bright Futures believes that every child deserves to be healthy, experience joy, have self-esteem, have caring family and friends, and believe that she or he can succeed in life. Seeking to respond to the current and emerging preventive and health promotion needs of infants, children, adolescents, families, and communities, Bright Futures offers a publication and a web site designed to meet those needs.

www.hrsa.dhhs.gov/childhealth
The Health Resources and Services Administration, under the U.S. Department of Health and Human Services, is working to improve the health status of children who are poor, uninsured, or who live where health care is in short supply. This web site provides valuable information on HRSA's child health program initiatives, state resources, model children's health and outreach programs, and child health insurance programs.

BEST COPY AVAILABLE

www.bphc.hrsa.dhhs.gov
The Bureau of Primary Health Care (BPHC) is part of the Health Resources and Services Administration, one of eight agencies under the Department of Health and Human Services. The Bureau seeks to increase access to comprehensive primary and preventive health care and to improve the health status of underserved and vulnerable populations who experience financial, geographic, or cultural barriers to care. The web site contains information about these vulnerable populations and outlines model community-based primary health care programs.

www.hcfa.gov/init/children.htm
The Health Care Financing Administration supports an informational Children's Health Insurance Program site. This site is intended to provide materials of interest to various audiences regarding the recent passage of the "State Children's Health Insurance Program," also known as Title XXI, as part of the Balanced Budget Act of 1997.

BOOK REVIEW

Everyone's Children
A Pediatrician's Story of an Inner-City Practice

"Day after day I am inspired. And day after day, I am given chance after chance to make a friend and make a difference, even if the differences are very small." So Claire McCarthy explains her decision to work at an inner-city health clinic serving some of the poorest families in Boston after completing of her residency at Harvard-affiliated Children's Hospital in Boston.

Everyone's Children, McCarthy's second book, chronicles her experiences as a pediatrician at Martha Eliot Health Center in Boston's Bromley-Heath Housing Development. The book is an account of what she has learned from the "incredible resilience, determination, and faith" of families she serves. For many of these families, she writes, "making it through each day is an achievement of which to be proud."

McCarthy describes her transition from viewing patients as "clinical dilemmas" to "people with ongoing lives"—lives that include poverty, violence, drug abuse, and other realities that must be taken into account when prescribing medical treatment. While many pediatricians take for granted that their patients have a safe place to sleep, enough food for the week, heat in their homes, and money or insurance to pay for medicine, McCarthy has had to learn to ask personal questions to ensure that families have the money and other resources needed to access the treatments she prescribes.

McCarthy also has realized that the traditional medical school model of "the shining doctor in the white coat who swoops in with the solution and some "words of wisdom" does not hold up when there is no solution, such as when a boy is diagnosed with incurable sickle cell anemia and the doctor must inform his mother; or when economic and social conditions of families cause and exacerbate health problems.

McCarthy chronicles her shift toward focusing on what she can do: listen compassionately to her patients, call the state department of social services to advocate for a family, give parents money to pay for medicine. McCarthy describes doing what many in the medical profession consider unthinkable: becoming personally involved in the lives of her patients. When one young immigrant mother is raped by her former boyfriend, McCarthy accompanies her to legal services, and opens her home to the mother and her son for the night. "Some situations demand that we react first as people and second as doctors," writes McCarthy.

Perhaps the most striking of McCarthy's discoveries is that she has a lot in common with the low-income families she sees: chiefly, the desire to be in a caring, stable home and community. She sees that she has much to learn from their experiences as parents, and from the dreams of their children.

While observing families working together to meet the needs of their children, she realizes, "We are not meant to parent alone. We are meant to be part of a community, where hands come out to guide us and help hold our children, where voices chime and mingle with ours, teaching us, comforting us. Our children are meant to grow up under many watchful eyes, and to have the love and encouragement of many."

A testament to the natural fit between family support and health care services, McCarthy's experiences lead to the inevitable conclusion that we all must play a part in caring for our communities' children, because our children—everyone's children—are our future.

1998, 217 pp., New York: Scribner

BEST COPY AVAILABLE

34

BEST COPY AVAILABLE

www.drugfreeamerica.org

From now on, you'll find a featured web site in each issue of FRCA *Report*. This time we're logging on to the Partnership for a Drug Free America, at www.drugfreeamerica.org.

The Partnership was formed in 1986 to reduce the demand for illicit drugs in America by using the media. Since its creation, close to 500 commercials have aired on television stations around the U.S. that help to counteract the message that drug use is cool or socially acceptable.The Partnership is funded by the Robert Wood Johnson Foundation and more than 200 private sector corporations. It is the primary campaign advisor (unpaid) to the White House Office of NAtional Drug Control Policy's (ONDCP) national anti-drug media campaign

By attacking and helping to prevent the problem of drug abuse, the Partnership for a Drug Free America helps reduce other risks to children and families' well-being, such as domestic and child abuse, homelessness, crime, and rising health care costs. The success of the Partnership so far has been the result of the combined efforts of parents, schools, and all members of the community.

This site offers a large variety of resources to help family support programs and communities conduct public education and activities to prevent and reduce drug abuse. Currently, the home page features a story on recent federal policy as well as several major areas:

Drug Information

A comprehensive database: What drugs look like, what they do

FAQs

Frequently-asked questions on drug-related topics

Help for Parents

Parenting: raising a drug-free child, and resources

Who We Are

Partnership for a Drug-Free America: How we do what we do

Partnership News

The latest news and information on Drug Use and PDFA

Other Sites on Drug Abuse Prevention

To learn more about substance abuse prevention and to join others in your community and nationwide in the fight against drugs, you can also visit:

Join Together
http://www.jointogether.org

Community Anti-Drug Coalitions of America
http://www.cadca.org

Substance Abuse & Mental Health Services Administration
http://www.samhsa.gov

The Partnership for a Drug Free America web site features ready-to-use information on how parents can help their children stay away from drugs, which family support programs can use in role-playing with parents or children, pamphlets and posters, and events that bring families and the community together to learn about drug abuse and how to fight and prevent it.

How to Talk to Your Kids About Drugs

These tips are published on the web site of the Partnership for a Drug Free America, at www.drugfreeamerica.org.

Listen Carefully

Student surveys reveal that when parents listen attentively to their children's concerns and feelings, kids feel comfortable talking to them, and are more likely to stay drug-free.

Encourage Choice

Allow your child plenty of opportunity to become a confident decision-maker. An eight-year-old can choose the outfit she wants to wear to school today. A nine-year-old is capable of deciding if she wants to invite lots of friends to her birthday party or just a close pal or two. A 12-year-old can choose whether she wants to go out for basketball or join the school band. As your child becomes skilled at making all kinds of good choices, both you and she will feel more secure in her ability to make the right decision concerning drugs and alcohol if and when the time arrives.

Provide Age-Appropriate Information

Make sure that the information you offer fits your child's age and cognitive level. When your six- or seven-year-old is brushing his teeth, you can say, "There are lots of things we need to do to keep our bodies strong and healthy, like brushing our teeth. But there are also some things that we shouldn't do because they can hurt our bodies, like smoking or taking any medicines when we are not sick."

An eight-year-old can understand a simple lesson about specific drugs, like marijuana or alcohol. If you're watching TV and marijuana is mentioned, take advantage of the opportunity to say something like "Do you know what marijuana is? It's a bad drug that can hurt your body." If you child has more questions, answer them. If not, let it go. Short, simple comments, initiated by you and repeated often enough will get the message across.

You can offer older children the same message, but add more drug-specific information. For example, explain to your 10- to 12-year-olds what marijuana and crack look like, their street names, and how they can affect the body. And don't be afraid to talk tough. You can say, "Cocaine and crack are very dangerous and illegal drugs that could kill you even if you take them just once."

If You Suspect a Problem, Seek Help

While kids under 12 rarely develop a substance problem, it can -and does- happen. If your child becomes withdrawn, loses weight, starts doing poorly in school, turns extremely moody, has glassy eyes—or if the drugs in your medicine chest seem to be disappearing too quickly —talk to your child and reach out to any of the organizations listed on this site. You'll be helping your youngster to a healthier happier future.

BEST COPY AVAILABLE

Family Portrait

Photo © 1997 Stephen Shames Matrix

WILLIE HINES HAS HIS ANNUAL CHECK UP at the medical clinic located between the high school and junior high in his family's Casey County, Kentucky, community. Health care is hard to come by in Casey County. In response, the Youth Services Center, part of a statewide effort in Kentucky, has arranged for a public health nurse to provide physical exams and health screenings for children at school. The center is able to provide other family members with referrals to health care providers.

This photos is part of a nationwide photo exhibit tour and public education campaign, Pursuing the Dream: What Helps Children and Their Families Succeed. The campaign includes a photo book that shows community-based programs in action, and is a collaboration among FRCA, award-winning photographer Stephen Shames, and Aperture Foundation. For information on how to get involved or bring the exhibit to your community, contact FRCA.

Board of Directors

Virginia L. Mason,
Executive Director

Bernice Weissbourd, President
Family Focus, IL

Amy Rassen, Chair
Jewish Family and Children's Services, CA

Ruth Massinga, Past Chair
Casey Family Program, WA

Mustafa Abdul-Salaam
Smith Whiley & Co.

MaryLee Allen
Children's Defense Fund, DC

Charles Bruner
Child and Family Policy Center, IA

Elizabeth Carlson
National Futures Association, IL

Robert Hassin
Boys & Girls Clubs of Chicago, IL

James Hinchliff
People's Energy Corporation, IL

Debra Lewis-Curlee
Federation for Community Planning, OH

Helen Nissani
Community Solutions for Children, WA

Ed Rivera
Cancer Treatment Research Foundation, IL

Bea Romer
First Lady of Colorado, CO

Khatib Waheed
St. Louis Community Partnerships, MO

Sylvia Yee
Evelyn and Walter Haas, Jr. Fund, CA

Ruth Zambrana
George Mason University, DC

FAMILY
RESOURCE
COALITION
OF AMERICA

20 NORTH
WACKER DRIVE
SUITE 1100
CHICAGO ILLINOIS 60606

312/338-0900
FAX: 312/338-1522
E-MAIL: frca@frca.org
WEB: www.frca.org

Address Correction Requested

NONPROFIT ORG.
U.S. POSTAGE
PAID
CHICAGO, IL
Permit No. 2358